

**MEMORY FUNCTIONING AND QUALITY OF
LIFE IN TEMPORAL LOBE EPILEPSY**

Roisin Jack

D.Clin.Psychol.

University of Edinburgh

August 2007



CONTENTS

	Page No.
ACKNOWLEDGEMENTS	I
DECLARATION	II
ABSTRACT	III
 <u>CHAPTER 1: INTRODUCTION</u>	
1.1 BACKGROUND	1-10
1.1.1 Historical Content	2
1.1.2 What is Epilepsy?	3
1.1.3 Prevalence	3
1.1.4 Economic Cost	4
1.1.5 Aetiology	4
1.1.6 Seizure Classification	5
(a) Partial or Focal Seizures	7
(b) Generalised Seizures	8
1.2 TEMPORAL LOBE EPILEPSY	10
1.3 PSYCHOLOGICAL ISSUES	11-15
1.3.1 Depression	12
1.3.2 Anxiety	13
1.3.3 Personality Disorder	13
1.3.4 Factors Influencing Psychosocial Issues	14
1.4 LOCUS OF CONTROL	15-17
1.5 COGNITIVE FUNCTIONING	17-24
1.5.1 Executive Functioning	19
1.5.2. Attentional Processes	21
1.5.3 Memory Functioning	22
1.6 TREATMENT APPROACHES	24-27
1.6.1 Anti Epileptic Drugs	24
1.6.2 Epilepsy Surgery	26
1.6.3 Cognitive Rehabilitation	26
1.7 QUALITY OF LIFE	27-32
1.7.1 Memory & Quality of Life	29
1.7.2 Locus of Control, Memory & Quality of Life	31
1.8 PRESENT STUDY: AIMS & HYPOTHESES	33-34

CHAPTER 2: METHOD

2.1	PARTICIPANTS	36-37
2.1.1	Inclusion Criteria	36
2.1.2	Exclusion Criteria	36
2.2	PROCEDURE	37
2.3	MEASURES	39-46
2.3.1	Memory Assessment (Wechsler Memory Scale – Third Edition)	
	(a) Logical Memory Subtest	41
	(b) Visual Reproduction Subtest	41
2.3.2	Assessment of Executive Function	42
	(a) Colour Trail Making Test Parts A & B	42
	(b) Controlled Word Association Test	43
	(c) Hayling & Brixton	44
2.4	OTHER AREAS ASSESSED	47-50
2.4.1	Hospital Anxiety and Depression Scale	47
2.4.2	Quality of Life in Epilepsy- 31	48
2.4.3	Multi Dimension Health Locus of Control Questionnaire	49
2.5	ETHICAL CONSIDERATIONS	50-51
2.5.1	Confidentiality	50
2.5.2	Distress During Assessment	51
2.5.3	Capacity Issues	51
2.5.4	Other Ethical Issues	51
2.6	DATA ANALYSIS	51-52

CHAPTER 3: RESULTS

3.1	BACKGROUND INFORMATION	54-57
3.1.1	Participants	54
3.1.2	Seizure Activity (Cause, Onset, Frequency)	55
3.1.3	Employment Issues	56
3.1.4	Anti Epileptic Drugs	56
3.1.5	Psychological Functioning	56
3.2	EXPLORATION OF HYPOTHESES	57-63
3.2.1	Hypothesis 1	57
3.2.2	Hypothesis 2	59
3.2.3	Hypothesis 3	61
3.2.4	Hypothesis 4	61
3.2.5	Hypothesis 5	63
3.3	OUTLIERS	64

<u>CHAPTER 4: DISCUSSION</u>	66-87
4.1 GENERAL ISSUES	66-69
4.2 HYPOTHESES	69-81
4.2.1 Hypothesis 1	69
4.2.2 Hypothesis 2	73
4.2.3 Hypothesis 3	77
4.2.4 Hypothesis 4	78
4.2.5 Hypothesis 5	80
4.3 CONCLUSIONS	81
4.4 METHODOLOGICAL CONSIDERATIONS	83
4.5 FURTHER RESEARCH	85

<u>REFERENCES</u>	88-104
--------------------------	---------------

APPENDICES

Appendix 1	Approval Letter from Local Ethics Committee
Appendix 2	Approval Letter from Research & Development
Appendix 3	Letter of Invitation to Participate
Appendix 4	Patient Information Sheet
Appendix 5	Consent Form
Appendix 6	Appointment Letter
Appendix 7	Background Information Form
Appendix 8	Quality of Life in Epilepsy (QOLIE-31) Version 1.0
Appendix 9	Multidimensional Health Locus of Control Scale (MHLC)

LIST OF TABLES

Tables 1 & 2:	International Classification of Seizures
Table 3:	Contributory factors to impaired QOL in people with epilepsy
Table 4:	Summary of Assessments
Table 5:	Gender & Age Range of Participants & Individuals Who Did Not Respond
Table 6:	Carstairs & Morris Index of Deprivation Score
Table 7:	Correlations between Executive Functioning Tasks & Quality of Life
Table 8:	Correlations between Immediate Memory (Visual & Verbal) & External Locus of Control Subscales
Table 9:	Correlations between Delayed Memory (Visual & Verbal) & External Locus of Control Subscales
Table 10:	Correlations between Multidimensional Health Locus of Control External Subscales & Quality of Life

LIST OF FIGURES

- Figure 1: Causes of epilepsy
- Figure 2: Participants' HADs Scores
- Figure 3: Participants' Overall QOL Scores
- Figure 4: Delayed Visual Memory & Quality of Life

ACKNOWLEDGEMENTS

There are several people I would like to thank for their assistance in the process of writing this thesis. Firstly I would like to thank both my academic and clinical supervisors Paul Morris and Dr Fiona Summers, clinical neuropsychologist for all their advice and support throughout the design, data analysis and write-up. I am also very grateful to Dr Linda Gerrie, consultant neurologist and Sheena Beevan, epilepsy nurse for their help in the patient recruitment process.

My sincere thanks go to all the patients who consented to take part in the study. Without their help and cooperation this research would not have been possible.

Finally, I would like to thank my boyfriend Paul and my family for all their encouragement and support throughout the course and in the years preceding it.

DECLARATION

“This thesis has been composed by myself and the work contained herein is my own.”

Roisin Jack

31/07/07

Date

D. Clin. Psychol. Declaration of own work

This sheet must be filled in (each box ticked to show that the condition has been met), signed and dated, and included with all assessments - work will not be marked unless this is done

Name: ROISIN JACK

Assessed work

Case Study

SSR

Essay Question Paper

Thesis

(please circle)

Title of work: MEMORY FUNCTIONING & QUALITY OF LIFE IN
TEMPORAL LOBE EPILEPSY

I confirm that all this work is my own except where indicated, and that I have:

- Composed and undertaken the work myself ☒
- Clearly referenced/listed all sources as appropriate ☒
- Referenced and put in inverted commas any quoted text of more than three words (from books, web, etc) ☒
- Given the sources of all pictures, data etc. that are not my own ☒
- Not made undue use of essay(s) of any other student(s) either past or present (or where used, this has been referenced appropriately) ☒
- Not sought or used the help of any external professional agencies for the work (or where used, this has been referenced appropriately) ☒
- Not submitted the work for any other degree or professional qualification except as specified ☒
- Acknowledged in appropriate places any help that I have received from others (e.g. fellow students, technicians, statisticians, external sources) ☒

I understand that any false claim for this work will be penalised in accordance with the University regulations ☒

Signature ROISIN JACK

Date 31/07/07

Please note:

a) If you need further guidance on plagiarism, you can:

i/ Speak to your director of studies or supervisor

ii/ View university regulations at <http://www.aaps.ed.ac.uk/regulations/Plagiarism/Intro.htm>

b) Referencing for all assessed work should be in the format of the BPS style guide, which is freely available from the BPS web site

ABSTRACT

Aims

The principal aim of this research was to explore whether individuals with temporal lobe epilepsy and significant memory dysfunction experienced lower quality of life. Executive functioning and locus of control issues in temporal lobe epilepsy were also explored.

Methodology

A within subject design was used to explore these issues. Twenty two participants with temporal lobe epilepsy underwent a neuropsychological assessment and completed 3 questionnaires: the Quality of Life in Epilepsy - 31 item questionnaire, the Multidimensional Health locus of control Scale and the Hospital Anxiety and Depression Scale. Pearson correlations were used to investigate relationships between variables.

Results

A significant positive relationship between memory functioning and quality of life was revealed. Executive functioning was also shown to be an important factor influencing quality of life and memory in temporal lobe epilepsy. The influence of locus of control on memory and quality of life was less than anticipated.

Conclusions

The results were discussed in relation to current literature and their implications in relation to clinical work and treatment were considered.

CHAPTER 1: INTRODUCTION

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND INFORMATION

1.1.1 Historical Context

Epilepsy has a considerable historical past. In ancient times, it was known as the "Sacred Disease" with many believing it a gift and others a curse from the gods. Throughout history, individuals with epilepsy have been stigmatised, shunned, and even imprisoned. In some countries, such as Tanzania, epilepsy continues to be associated with possession by evil spirits and/or witchcraft, and is believed by many to be contagious (Jilek-Aall, 2006). The Greek philosopher Hippocrates (460-377 BC) was the first to suggest that epilepsy originates from the brain rather than from some kind of divine higher power:

*"It is thus with regard to the disease called sacred: it appears to me to be in no way more divine nor more sacred than other diseases...
The brain is the cause of this affliction."* (Hippocrates, 460-377 BC)

A possible link between epilepsy and greatness has fascinated biographers and physicians for centuries. Many figures from history, including Hercules, Van Gogh, Lewis Carol and Napoleon have been thought to have epilepsy. Saints and other religious figures have also been linked to the condition (Dewhurst & Beard, 2003). Peter Fenwick (1994) has questioned the widespread labelling of famous figures with epilepsy and believes this may "owe more to the enthusiasm of their authors than to the true scientific understanding" (pp.1). In a more recent detailed review of the subject, neurologist John Hughes (2005) concluded that the majority of famous people alleged to have epilepsy, probably did not have the condition.

1.1.2 What is Epilepsy?

The words "epilepsy" and "epileptic" are of Greek origin and have the same origin as the verb "epilambanein," meaning "to seize" or "to attack". Epilepsy is one of the most commonly known neurological conditions. It is a "chronic disorder characterised by recurrent seizures" (Gestaut, 1973) and "reflects an episodic disturbance of behaviour or perception arising from hyper excitability and hyper synchronous discharge of nerve cells in the brain that can be associated with a variety of aetiologies" (Lezak et al, 2004). Van Rijckevorsel (2006) stresses the point that epilepsy should not be considered a disease but rather as a symptom indicating, rather than causing, brain dysfunction.

1.1.3 Prevalence

Up to 5% of the world's population may have a single seizure at some time in their lives (often as a result of high temperature or severe dehydration), but a diagnosis of epilepsy is reserved for those who have recurring seizures or at least two unprovoked ones. The World Health Organisation estimates that approximately 50 million people in the world have epilepsy at any given time (WHO, 2001). The prevalence figures are generally higher in developing countries compared with developed countries. The reason for this is unclear, although social deprivation has been put forward as an explanation (Sander & Shorvon, 1996). Interestingly, recent data suggests that people from socio-economically deprived backgrounds in developed countries are also more prone to developing epilepsy (Sander, 2003).

The National Epilepsy Society (2006) indicates that one in every 130 people in the UK have epilepsy, meaning that there are currently approximately 450,000 people with epilepsy in the UK. In Scotland, it is estimated that there are 20,000-40,000 people with active epilepsy and between 2,000 and 3,500 newly diagnosed cases each year (SIGN, 2003). Epilepsy can affect anyone at any age, and males appear more prone to developing it than females (Cull & Goldstein, 1997).

1.1.4 Economic Cost

The Clinical Guidelines for the Management of Epilepsy, published in 2004 by the National Institute for Health and Clinical Excellence (NICE), reported that the medical cost of treating people with epilepsy in England alone was over £23 million, rising to almost £28 million across the UK. The non-medical costs (for example, social services and care costs) are reported to be significantly higher at more than £111 million in England and over £132 million across the whole of the UK, bringing the combined costs across the UK to over £160 million. These figures emphasise the importance of exploring non-medical issues as well as medical ones in epilepsy.

1.1.5 Aetiology

Epilepsy is characterised as being idiopathic, cryptogenic or symptomatic. Idiopathic epilepsies have no known aetiology and are not usually associated with other neurological disorders, and consequently, neuropsychological deficits are generally absent (Perrine et al, 1991). The aetiology of cryptogenic epilepsy is also unknown, but patients' neurological and neuropsychological profiles are usually atypical. It is generally accepted that 60-70% of all epilepsies have no clear cause

and their aetiology remains a key issue for researchers (Sander, 2005). Seizures with known aetiology are referred to as symptomatic. Where causes can be identified, they may be varied in nature (Cull & Goldstein, 1997). A number of individuals have attempted to review and categorise the causes of epilepsy (Lishman, 1997; Sander et al 1990). Figure 1 illustrates the main causes revealed in a community-based study of epilepsy in the United Kingdom (the National General Practice Study of Epilepsy) (Sander et al 1990):

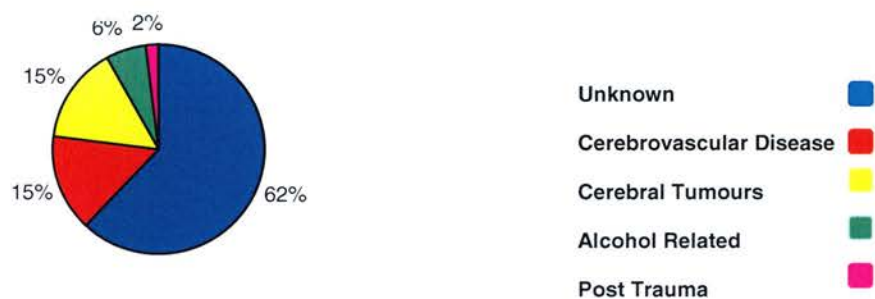


Figure 1: Causes of epilepsy as found in Sander et al (1990) study

Other causes of epilepsy are rare but may include birth injury or congenital malformations, infections, and neurodegenerative disorders.

1.1.6. Seizure Classification

Seizure types are categorised according to whether they are localised (partial or focal onset seizures) or distributed across the cortex (generalised seizures). Brain scans and electroencephalographic (EEG) often provide useful information for those trying to diagnose and differentiate between the various seizure types (Fowler, 2000; King 1998). However many seizures are difficult to classify. Chadwick (2005) highlights that seizure classification can be biased, and is usually most accurate in patients with

frequently occurring severe epilepsy, where there is a greater likelihood of observing an EEG correlate of the seizure. Tables 1 and 2 summarise the classification of seizures as presented by the International League Against Epilepsy (1981). Although several revisions have been suggested this classification is still the most commonly used:

Partial Seizures (beginning locally)	
Simple Partial (consciousness not impaired)	Complex Partial (impairment of consciousness)
With motor symptoms	Beginning as simple partial seizure
With somatosensory or special sensory symptoms	Impairment of consciousness from outset
With autonomic symptoms	(a) Impairment of consciousness only
With psychic symptoms	(b) With automatism

Generalised Seizures (across the brain)					
Absence	Myoclonic	Clonic	Tonic	Tonic-Clonic	Atonic
Typical or Atypical	Single/ multiple jerking movements	Rhythmic jerking movements of the arms and legs	Sudden increased tone	Previously grand mal	Sudden decrease in muscle tone
Abrupt onset	Quick recovery	Rare	Stiffening of arms and legs	Most common generalised seizure	Fall to ground
Vacant appearance		Varying duration	Less than 20 secs	Loss of consciousness	Rapid recovery
Momentarily unconscious				Rarely preceded by warning	
More common in children & adolescents				Sudden contraction of muscles	

Tables 1 & 2: International Classification of Seizures

1.1.6 (a) Partial or Focal seizures

Approximately two thirds of the epilepsy population experience partial seizures (Martin et al, 2006). These begin locally in the cortex and are often preceded by an aura (a psychic or sensory disturbance that warns individuals that they are about to have a seizure). Partial seizures are further divided into partial and complex seizures depending on the extent to which consciousness is affected. If consciousness is unaffected, then it is termed a simple partial seizure. The most common sites of origin for simple partial seizures are within the frontal or temporal lobes (Chadwick, 2005).

Complex partial seizures are differentiated from simple partial seizures by varying degrees of consciousness. The individual loses awareness during a complex partial seizure because the seizure spreads to involve both temporal lobes. This impairment in consciousness may be preceded by symptoms of a simple partial seizure, usually by those associated with the temporal lobe region. However, in some circumstances consciousness may be lost from the outset. Such seizures are often associated with repetitive stereotyped behaviours or ictal automatisms (for example, fidgeting, lip smacking or chewing and clothes picking). Sometimes, more complex behaviour is exhibited, which in extreme circumstances can lead to inappropriate behaviours such as indecent exposure or shoplifting. Forced repetitive thoughts, changes in mood, hallucinations and/or feelings of déjà vu are sometimes experienced, as are postural changes. Complex partial seizures are frequently followed by post-ictal activity (for example, confusion, reduced attention and/or impaired coordination) (Chadwick, 2005). Both simple and complex partial seizures may spread more generally to

involve both hemispheres and result in a tonic-clonic seizure (secondary generalised seizure).

1.1.6 (b) Generalised seizures

Approximately one third of all patients with epilepsy suffer from generalised seizures (Martin et al, 2006). Generalised seizures commence bilaterally (that is both hemispheres are affected) and consciousness is usually lost suddenly, so that the patient experiences no aura. They are categorised according to the effect they have on the body, and they all involve loss of consciousness. They include absence (petit mal), myoclonic, clonic, tonic, tonic-clonic (grand mal), and atonic seizures.

Typical absences (previously called petit mal) are characterised by a sudden, cessation of ongoing activity when the individual loses contact with their environment and stops activity. There may be some minor myoclonic activity around the eyelids. These attacks may last up to 30 seconds and come to a sudden end with no post-ictal confusion (Chadwick, 2005).

Atypical absences usually occur in symptomatic epilepsy in individuals with pre-existing brain damage. They are more prolonged and are often associated with myoclonic activity or atonic attacks, which may result in the individual being thrown to the ground, frequently suffering trauma (Chadwick, 2005).

Myoclonic seizures occur as single and/or multiple jerking movements, which may be generalised to the face, trunk, or one or more limbs or muscle groups. These

contractions are especially common on falling asleep or waking, and occur as part of idiopathic generalised epilepsy or as part of a mixed seizure disorder such as Lennox-Gestaut syndrome. They are also seen in Creutzfeldt-Jakob disease (Cull & Goldstein, 1997).

Tonic-clonic seizures (previously called grand mal) are the most common form of generalised seizure. They may occur in a primary fashion or following generalisation after a partial seizure. When they are of primary origin, the patient does not experience any aura but may describe a more non-specific and longer lasting prodrome of general malaise (Chadwick, 2005). Tonic seizures may occur without the clonic component, and similarly clonic seizures may occur on their own. In the tonic stage muscles become rigid and fixed and in the clonic stage muscles alternately contract and relax.

Atonic seizures are characterised by a decrease in muscle tone and the person falling to the ground. These are often referred to as drop attacks and need to be distinguished from similar attacks that occur in narcolepsy/cataplexy (Cull & Goldstein, 1997).

There are many different epilepsy syndromes, each presenting with its own unique combination of seizure type, typical age of onset, EEG findings, treatment, and prognosis. These include frontal lobe, temporal lobe, juvenile myoclonic, occipital lobe, Lennox-Gestaut Syndrome, childhood absence epilepsy and infantile syndrome (West Syndrome). There is a tendency for researchers in this area to use the term

‘epilepsy’ without specifying type and this can make interpretation of data difficult.

In this study, the focus will be on temporal lobe epilepsy.

1.2 TEMPORAL LOBE EPILEPSY

Temporal lobe epilepsy was first recognised by Hughling Jackson in 1881. The International League Against Epilepsy (1981) defines temporal lobe epilepsy as a condition characterised by recurrent unprovoked seizures originating from the medial or lateral temporal lobe. Temporal lobe epilepsy can manifest itself as simple or complex partial seizures. It is the most common type of seizure disorder, occurring in approximately 40-60% of patients with epilepsy. Patients with temporal lobe epilepsy often present with the following: febrile seizures; early onset in childhood; early anoxic episodes in childhood; family history of epilepsy; resistance to antiepileptic medication and mesial temporal sclerosis on neuroimaging, (although more widespread abnormalities can be present) (Berg et al, 1996). Mesial temporal sclerosis involves neuronal loss and gliosis (scarring) within the mesial temporal structures.

Diagnosing epilepsy is often difficult and misdiagnosis is common (Beghi, 2007). Diagnosing temporal lobe epilepsy is challenging because it is difficult to be accurate about exactly where seizures originate from in the brain. Classically the expression more often refers to mesial temporal epilepsies rather than lateral temporal epilepsies. Without in depth electrode studies and/or a clear-cut abnormality on scan with supporting evidence from surface EEG that the structural abnormality seen is also the site of seizure onset it is impossible to state this diagnosis with absolute

certainty. Many have an aura suggestive of mesial temporal onset and are therefore viewed as having "probable temporal lobe epilepsy". In reality, many neurologists often avoid using the term stating instead what type of seizure a patient experiences for example, "complex partial seizures with or without secondary generalisation" and where relevant giving a description of the individual's aura.

1.3. PSYCHOLOGICAL ISSUES

It is becoming increasingly recognised that epilepsy has profound social and psychological consequences (Au et al, 2002; Thomson & O'Toole, 2005). Arguably, the impact of these psychosocial difficulties is more significant than the physical symptoms of the condition (Baker et al, 2000; MacLeod & Austin, 2003). A number of factors leading to the neuropsychiatric features of epilepsy have been suggested. These include the possibility that epileptiform discharges originating from the central nervous system provoke emotional responses; the functional limitations associated with seizures; perceived social stigma; and/or the possible adverse effect of antiepileptic drugs (Bortz 2003).

Up to 50-60% of patients with chronic epilepsy have mood disorders, with anxiety and depression being particularly prevalent (Beyenburg et al, 2005). The general rate of mood disorder in epilepsy patients has been shown to be higher than both the general population and patients with other chronic medical conditions such as diabetes and asthma (Blum et al, 2002; Bortz, 2003; Moore & Baker, 2002). In addition, people with epilepsy are more likely to be unemployed or underemployed, have lower rates of marriage and experience greater social isolation (Jacoby et al,

1996; Moore & Baker, 2002). In the UK, many still feel that revealing their condition will deter their employers who may view them as unreliable and likely to cause accidents (Usiskin, 2005). Research indicates that individuals with epilepsy are up to twice as likely to be unemployed and are frequently subject to underemployment, relative to their skills and qualifications. This has consequences for their financial status and psychological well-being (Baker, 2005).

A number of studies have reported an increased rate of psychiatric disturbance in patients with temporal lobe epilepsy, compared with patients with other types of epilepsy (Perini et al, 1996; Quiske et al, 2000). However, other researchers have failed to document an association between temporal lobe epilepsy and psychiatric symptoms (Fedderson et al, 2005; Issacs et al, 2004; Swinkels et al, 2001).

1.3.1 Depression

Hippocrates was the first to suggest a bi-directional relationship between epilepsy and depression. He wrote that "melancholics ordinarily become epileptics, and epileptics melancholics" (Lewis, 1934). Recent studies have explored the possibility that the two disorders have a bi-directional relationship: that is, not only are patients with epilepsy at greater risk of developing depression, but patients with depression have a greater risk of developing epilepsy (Frucht et al, 2000; Hesdorffer et al, 2000; Schmid-Schonbein, 1998; Taher et al, 2005). It has been proposed that this relationship may be due to disturbances in the central nervous system's serotonergic activity (Hesdorffer et al, 2006).

A review by Kanner (2003) indicated that the prevalence of depression ranges from 20-55% in patients with ongoing seizures and from 3%-9% of patients with well-controlled seizures. Another review summarised published prevalence rates of major depression in-patients with chronic epilepsy. They reported estimates ranging from 8-48% and both mean and median rates of approximately 30% (Bortz, 2003). Several studies indicate that depression is more frequently reported in temporal lobe epilepsy and left-sided foci, although not all studies support this finding (Harden, 2002). Suicide has also been reported to be 4-5 times more common in epilepsy, as has hospitalisation, especially in temporal lobe epilepsy where seizures are frequently uncontrolled (Grabowska-Grzyll et al, 2006).

1.3.2 Anxiety

Much attention has focused on depression, although a systematic review conducted by Beyenburg et al (2005) indicated that anxiety “may actually be more common and equally disabling” (Goldstein & Harden, 2000; Marsh & Rao, 2002; Vazquez & Devinsky, 2003). This review points to evidence as far back as 1971, when Currie et al (1971) recorded a 19% prevalence of anxiety disorder, compared with an 11% prevalence of depressive disorder, in patients with temporal lobe epilepsy. Vazquez and Devinsky (2003) summarised the prevalence of anxiety in epilepsy as ranging between 15-25%, when using well-defined diagnostic criteria for anxiety disorders.

1.3.3. Personality disorder

An increased prevalence of personality traits or disorders is frequently found in epilepsy patients, with estimates of co-morbidity somewhere between 29-50%

(Lishman, 1997; Swinkels et al, 2003, 2006; Schwartz & Cummings, 1988). Individuals with epilepsy appear to be at an increased risk of developing psychotic conditions compared with the general population, particularly schizophrenia-like and paranoid states (Aldencamp & Hendriks, 2000).

1.3.4 Factors Influencing Psychosocial Issues

Research has identified a number of factors that may predict psychosocial adjustment in epilepsy. These include clinical (age at onset, seizure type, seizure frequency, and severity), demographic (age, sex, employment and marital status) and neuropsychological factors (memory, executive functioning) (Baker et al, 1996, Jacoby et al, 1996).

Many negative connotations are attached to epilepsy. Seizures do not conform to society's expectations of predictability and self-control in everyday behaviour (Shafer, 2002). As a result, people with epilepsy are often prevented from participating in activities, which can jeopardise both their emotional wellbeing and development of social relationships. In addition, seizures themselves (especially if they are uncontrolled) can restrict an individual's activity and therefore their level of social contact for example, seizures may prevent a person from driving.

Uncertainty and a lack of control constitute a common theme in the experience of patients with epilepsy and should be considered a significant aetiological factor in the development of psychosocial problems in epilepsy (Au et al, 2002). Baker (2001) highlights the unpredictable nature and course of epilepsy. This can cause

patients with epilepsy to feel that they have a lack of control over seizure activity and these feelings can often become generalised to other aspects of their lives (Au et al, 2002; Gehlert, 1994). Over time, patients may begin to believe that their health is significantly more a matter of chance than of their own doing.

It is importance to stress the negative impact that these psychological difficulties can have on an individual's everyday functioning and quality of life (Janukainen, 1995). One of the key challenges to those working in the epilepsy field is how to influence the impact of these factors and in so doing ameliorate the deleterious impact they can have.

1.4 LOCUS OF CONTROL

The concept of locus of control was originally developed in the 1950s (Rotter, 1954). Locus of control refers to an individual's perception about the underlying main causes of events in his/her life. The concept is often divided into two categories namely external and internal locus of control. People with a strong internal locus of control believe that success or failure is due to their own efforts whereas externals believe that events are controlled by luck, chance, or powerful others. Those classified as having higher external locus of control consider their own efforts as having relatively little effect on the amount of reinforcement they receive. There is research to suggest that such individuals are more likely to be stressed and suffer from depression, as they are more aware of work situations and life strains (Benassi, Sweeney & Dafour, 1988; Hogg & Vaughan, 1995).

An alternative model to Rotter's has been put forward (Levenson, 1973). Rather than view locus of control as one-dimensional (internal to external), it suggests that there were three independent dimensions: internality, chance, and powerful others. According to this model, an individual can hold each of these dimensions of locus of control independently and/or at the same time. For example, an individual might simultaneously believe that both oneself and powerful others influence outcomes but that chance does not.

Since its introduction, the locus of control construct has undergone considerable elaboration and several context-specific instruments have been developed. Health researchers in particular have embraced locus of control as a concept for explaining behavior. Among the most widely used health-specific measures is the Multidimensional Health Locus of Control Scales (Wallston et al, 1978). This instrument retains Levenson's three dimensions but concerns outcomes that are specifically related to health and illness, such as staying well or becoming ill.

The Multidimensional Health Locus of Control scales have met criticism on a more general basis, and the utility of the concept of locus of control is often questioned (Wallston, 1992). However, many support its use and argue that perceived control is a promising construct despite these widely recognised theoretical and methodological limitations (Norman et al, 1995; Wallston, 2001).

Epilepsy is a disorder characterised by loss of control (Matthews et al, 1982). For many people with the condition, seizures may occur at any time with little warning.

The constant threat of a sudden, unpredictable loss of control has been thought to be a central aspect of the condition (Baker, 2001). Repeated exposure to uncontrollable and unpredictable adverse events such as seizures has been hypothesised to diminish a person's sense of control over both environmental and internal factors, resulting in a pervasive sense of "learned helplessness" (Seligman et al, 1975). This may lead to an attributional style where patients come to believe that they have little internal control over events and/or their symptoms and they attribute their lack of control and other negative events or symptoms to external causes (chance and the actions of others). Compared with other chronic conditions, research has indicated that epilepsy is associated with a significantly greater external locus of control (Matthews & Barabas, 1981).

1.5 COGNITIVE FUNCTIONING

Cognition can be defined as the capacity of the brain to process information accurately and to program adaptive behaviour (Van Rijckevorsel, 2006). Cognition fulfils an essential role in our lives and personality and can be potentially affected by a variety of central nervous system processes especially those which are chronic such as epilepsy (Trimble et al 1994). Overall, individuals with epilepsy tend to report and demonstrate cognitive dysfunction compared to age matched controls in the general population (Smith et al, 1996; Trimble et al, 1996). A number of authors highlight that cognitive profiles in different epilepsies demonstrate great diversity and are probably as heterogeneous as the epileptic syndromes themselves (Elger et al, 2004; Gupta & Naorem, 2003; Mameniskiene, 2006). However, common complaints include memory problems, decreased levels of attention and

concentration, slowness in thinking and lack of motivation (Bennett, 1992). Cognitive dysfunction in patients with epilepsy can be a major contributor to the burden of the disease and can significantly disrupt many aspects of a person's life. Early onset may result in more generalised cognitive dysfunction, as the maturing brain is affected and organisational processes encumbered. Later onset is often associated with greater partial impairment especially in memory (Helmstaedter & Gates, 2006). In addition, there is evidence to suggest that cognitive problems may actually antedate a diagnosis of epilepsy. Although research is limited in this area and the mechanisms which might explain this effect remain unclear (Hermann & Seidenberg, 2007).

Cognition appears to be affected by multiple factors including seizure aetiology, seizure control, seizure frequency and duration, seizure severity, hereditary factors, psychosocial conditions and anti epileptic drug effects (Lennox, 1942; Lesser et al, 1986; Loring & Meador, 2001; Meador, 2001).

A large body of evidence now exists detailing the neuropsychological deficits that often accompany temporal lobe epilepsy (Exner et al, 2002). Interestingly, the duration of the disorder in years appears to be positively correlated with the degree of neurocognitive dysfunction (Strauss et al, 1995). Recent examinations of the neurodevelopmental impact of childhood onset temporal lobe epilepsy supports the presence of widespread neurocognitive dysfunction as well as diffuse brain structure abnormalities (Hermann et al, 2002).

1.5.1 Executive Functioning

Executive functioning relates to a person's capacity to engage successfully in independent, purposive, self-serving behaviour (Lezak et al, 2004). Exploration of neuropsychological deficits in temporal lobe epilepsy has tended to focus on memory problems however, it is becoming increasingly recognised that difficulties in executive functioning often arise (Hermann & Seidenberg, 1995). Studies correlating neuropsychological testing and functional brain imaging support this view by confirming executive dysfunction in temporal lobe epilepsy patients (Herman et al, 1988; Jokeit et al, 1997).

Studies have revealed that patients with temporal lobe epilepsy experience difficulty with the Wisconsin Card Sorting Test (WCST) (Martin et al, 2006). This is a well-known test of executive functioning that particularly focuses on set-shifting ability. Traditionally, patients with any sort of frontal lobe lesion are said to generally perform poorly on this test. Interestingly, Hermann et al (1988) reported that 74% of non-dominant temporal lobe epilepsy patients and 39% of patients with dominant temporal lobe epilepsy foci performed on the WCST in a manner that would normally be considered 'frontal'. Horner et al (1996) also reported a high number of perseverative errors by temporal lobe epilepsy patients on the WCST (irrespective of lateralisation of focus). Several factors may affect WCST performance in temporal lobe epilepsy patients including side of focus, age of onset of epilepsy (Strauss et al, 1993) and mood (Seidenberg et al, 1995).

Another study comparing executive functioning in frontal and temporal lobe epilepsy patients indicated that in temporal lobe epilepsy, seizure frequency was primarily responsible for errors displayed in the inhibition/switching condition (McDonald et al, 2005). This study indicated that no other demographic, disease-related, or psychological factors contributed to the participants' performance. This finding is supported by other research indicating that higher seizure frequency is associated with greater cognitive dysfunction in temporal lobe epilepsy, possibly through secondary neuronal metabolic and/or structural deterioration (Dodrill, 1986). Frequent seizure activity in patients with temporal lobe epilepsy may be associated with the development of white matter abnormalities or metabolic changes in the frontal lobes that are undetected on standard imaging, but which nevertheless contribute to executive dysfunction (Hermann et al, 2003).

A number of hypotheses regarding executive dysfunction in temporal lobe epilepsy have been identified (Bougakov, 2005). The nociferous hypothesis states that the epileptogenic cortex adversely affects the extratemporal regions that mediate executive system abilities, thereby resulting in performance deficits. Related to this is the possibility that executive dysfunction may be explained by the connections between the temporal and frontal regions. In addition, temporal lobe seizures may spread via the frontal regions, resulting in dysfunction from both regions. Alternatively, the hippocampal hypothesis suggests that such impairments are due to direct hippocampal involvement in the mediation of executive function and that performance deficits are directly attributable to hippocampal pathology. Bougakov's (2005) study supported the view that individuals with temporal lobe epilepsy have

executive dysfunction but did not provide a satisfactory explanation about the mechanisms underlying this.

In summary, subsets of patients with temporal lobe epilepsy, particularly those with left medial temporal sclerosis, do appear to exhibit executive dysfunction especially on demanding, multilevel executive tasks. The nature and origin of these difficulties requires further explanation. The degree of this executive dysfunction in temporal lobe epilepsy patients may depend on seizure frequency or related factors (for example, prefrontal white matter damage secondary to frequent seizure propagation) (McDonald et al, 2005).

1.5.2. Attention

Attention is the is the cognitive process involved in perceiving, selecting and maintaining or detaching focus from stimuli. Impairments in attention are among the most common manifestations of brain damage and the impairment of sustained attention is consistently described in epilepsy (Van Rijkevorsel, 2006). It is difficult to consider attentional processes without reference to working memory. This refers to the capacity of to hold and manipulate information for a short period of time. Research suggests that working memory is not commonly not affected by medial temporal region damage in adult humans and animals. However, long-term memory, the ability to store information for later recall, is impaired following damage to or disruption of components of the medial temporal region. In general, delays greater than 15–30 seconds on these tasks are sensitive to medial temporal

damage (Hershey et al, 1998). However, this may differ across specific task demands, materials and the nature of the lesion.

1.5.3 Memory Functioning

Memory refers to the ability to store, retain, and subsequently recall information. It is not a single system but rather there are many different types including working, long term, remote, prospective and procedural memory. Memory dysfunction is the most frequently reported cognitive problem in epilepsy (Hendriks et al, 2002; Hermann et al, 1996; Leritz, 2006). The prevalence of memory problems in patients with refractory epilepsy has been estimated to be between 20-50% (Halgren et al, 1991). Ponds and Hendrik (2006) analysed subjective memory complaints in a sample of 252 epilepsy patients with intractable seizures, using a standardised memory questionnaire for patients with epilepsy. Participants particularly complained about memory problems that reflected 'absent minded behaviour', such as mislaying items. In other words, they struggled with the retrieval of complex meaningful episodic information. These results appear to be comparable with other studies (Helmstaedter, 2001; Thomson & Corcoran, 1992).

Epilepsy carries a high risk of memory dysfunction on both organic and behavioural grounds. Underlying brain pathology is probably the most influential cause of memory disturbance in epilepsy. Although, evidence indicates that several other factors may also cause or exacerbate memory problems including type of epilepsy, age at onset and duration, seizure activity, anti-epileptic drugs, surgery and mood (Thomson, 1997).

Decades of research have provided substantial evidence of memory difficulties in patients with temporal lobe epilepsy, including deficits of encoding, storage and retrieval of new information (Bortz, 2003; Leritz et al, 2006). These findings are unsurprising, given the associated underlying neuroanatomy involved in these seizures, including the hippocampus and surrounding medial temporal lobe structures. Both human and animal studies have demonstrated that damage to the hippocampus particularly impairs memory performance (Squire, 1992). Early diagnosis and treatment is important as successful control of temporal lobe epilepsy can reduce or prevent further damage.

Ponds and Hendriks (2006) indicate that lateralisation of the epileptogenic focus is a crucial risk factor in determining both the severity and nature of memory dysfunction. They indicate that patients with a unilateral left temporal lobe epileptic focus are at a significantly increased risk of experiencing memory difficulties, compared with patients with right temporal lobe epilepsy. However, Moore and Baker (2002) highlight the results of studies of people with well-lateralised temporal lobe seizure focus and those who have undergone surgical resection of the temporal lobes (Delaney et al, 1980; Ellis et al, 1991; Jones-Gottman, 1987). Such studies consistently support the generally held view in neuropsychology of lateralised material specific memory deficits. This indicates that damage to left temporal lobe leads to difficulties remembering verbally presented information (Helmstaedter et al, 1997) but right temporal lobe damage adversely affects memory for non verbal (usually visuospatial) information (Baxendale et al, 1998). Moore and Baker (2002) go on to say that these findings have not always been replicable. Patients who have

experienced bilateral temporal lobe damage may become amnesic and be unable to form new memories.

1.6 TREATMENT APPROACHES

1.6.1 Anti Epileptic Drugs (AEDs)

The majority of people who develop epilepsy (70-80%) will become seizure free with AED therapy (Sander, 1993). However, seizures in approximately one third of patients are more resistant to AEDs and require higher doses or polytherapy (more than one type of AED). A number of studies report that patients taking a number of different AEDs have significantly poorer memory performance (Elixhauser et al, 1999; Giovagnoli et al, 1997; Lammers et al, 1995).

The study of the neuropsychological effects of AEDs is complex because the potential adverse and beneficial effects may compensate for each other. For example, AEDs may impair memory, but may also bring benefit to memory through seizure suppression. The current literature can only give an estimate of the side effects of AEDs, due to methodological errors in design and an obvious lack of consistency in assessment procedure (Cochrane et al, 2006).

Each drug has a unique pharmacodynamic and tolerability profile (Sander, 2005). Slowing of mental or motor speed and attention deficits are documented affects of several frequently used AEDs including carbamazepine, phenbarbital and phenytonin (Kwan & Brodie, 2001). AEDs may adversely impact memory functions primarily because of their detrimental effects on attention and vigilance (Helmstaedter, 2001).

Despite the fact that many patients on long-term AED therapy report cognitive side effects studies to confirm this have been contradictory and confounded by the effects of chronic epilepsy (Cochrane et al, 1998; Vermeulen & Aldenkamp, 1995).

The National Institute of Clinical Excellence (2004) has based its standards for epilepsy prescribing upon the available trial evidence together with calculations of cost effectiveness. It concludes that carbamazepine should be the first choice for focal/partial epilepsy and sodium valproate should be the first choice for generalised epilepsy. However, the evidence base is surprisingly small, with few studies comparing these drugs against newer AEDs.

The study of Standard and New Antiepileptic Drugs (SANAD) was a multi-centred randomised control trial of longer-term clinical outcomes and cost effectiveness of standard and new antiepileptic drugs. It involved 2,400 patients with all types of epilepsy seen over several years (randomisation took place between 1999 and 2004 with follow up until 2005). It was sponsored by NHS Research & Development Health Technology Assessment Programme to determine whether these new drugs are to be preferred in the everyday management of people with epilepsy to the previously available standard treatments. Within this study the possible neuropsychological affects of standard versus new antiepileptic drug treatment in newly diagnosed patients has been explored. This was the largest study of its kind involving many key names from the world of epilepsy research (Marson et al, 2007). In general, results indicate that newer antiepileptic drugs appear to display minor or no cognitive side effects.

1.6.2 Epilepsy surgery

Surgical treatment is increasingly being used to help patients with intractable epilepsy. This involves surgical resection of epileptogenic brain tissue of patients with intractable seizures of focal origin. A number of different surgical procedures are now available, including partial removal of the amygdala and hippocampus, removal of a significant amount of the temporal lobe, partial separation of the two hemispheres of the brain and removal of a significant amount of one hemisphere of the brain. Approximately 80% of individuals with complex-partial seizure disorder, especially those of temporal origin, either become seizure-free or enjoy a significant reduction in seizure frequency (Andelman et al, 2004; Engel et al, 1997). Neuropsychological assessment to delineate the epileptogenic lesion plays a key role in insuring and evaluating the success of such procedures.

1.6.3 Cognitive Rehabilitation

This aspect of treatment focuses on the management of observed cognitive dysfunction in epilepsy rather than on seizure reduction and control. Wilson (1997) defines cognitive rehabilitation as “any intervention strategy or technique which intends to enable clients or patients, and their families to live with, manage, by pass, reduce or come to terms with cognitive deficits precipitated by injury to the brain” (pp.117). In recent years, there has been increased interest in this area. However, there is a lack of large-scale controlled studies examining the efficacy of the various rehabilitation techniques and most of the evidence for this approach comes from traumatic brain injury literature (Shulman & Barr, 2002). Its application and exploration in the field of epilepsy remains largely neglected with a few exceptions

(Aldenkamp & Vermeulen, 1991; Gupta & Naorem, 2003; Hendriks, 2001). Overall the literature exploring cognition and epilepsy has been criticised for focusing too much on its characterisation and description rather than treatment (Hermann & Seidenberg, 2007).

1.7 QUALITY OF LIFE

Quality of life is a broad concept that encompasses a person's feelings of satisfaction with various interacting areas of their daily functioning. Generally, it is accepted that quality of life needs to address (at a minimum) satisfaction with physical, cognitive, emotional, social and economic functioning (WHO, 1980; Hornquist, 1982; Spitzer, 1987; Fallowfield, 1990). Health care professionals and patients with epilepsy often tend to underestimate the impact that quality of life can have on a person's well being.

Health related quality of life refers to the way in which patients function and their perception of well being in physical, mental and social domains of life. It emphasises the patients' experience of health and illness and looks beyond traditional medical assessment (Au et al, 2002). Evaluation of the impact of treatment for epilepsy on health related quality of life is essential because functioning and wellbeing are the outcomes that are most important to patients (Cramer, 1999; Devinsky et al, 1995). It has long been recognised that health-related quality of life has a major impact on successful epilepsy treatment, but research in this area remains scarce.

Kendrick (1997) suggests 3 key factors that may influence the quality of life of individuals with epilepsy. These are summarised in table 3:

Factor	Specific Items
Medical	Seizure occurrence (frequency, severity)
	Medication (intrusion/side effects)
	Hospitalisation (in-patient/out-patient)
Social	Stigmatisation (felt/enacted)
	Family dynamics (over protection)
	Employment difficulties
	Legal instructions (driving)
Psychological	Cognitive Deficits (memory, concentration)
	Intellectual decline
	Psychiatric (depression, anxiety, behavioural disturbance)

Table 3: Contributory factors to impaired Quality of Life in People with Epilepsy (Kendrick, 1997)

The occurrence of recurring, unpredictable seizures is undoubtedly a major factor affecting the life of a person with epilepsy. Seizure frequency and type and fear of seizures have been revealed as significant predictors of well being and quality of life in people with epilepsy (Boylan et al, 2004; Johnson et al, 2004; Sillanpaa et al, 2004). Several studies have found a significant association between quality of life improvement and seizure reduction following temporal lobe surgery (Engel, 1997; McLachlan et al 1997; Spencer & Spencer, 1985). Adults with well-controlled epilepsy have been shown to have a similar quality of life compared to people with other chronic illnesses (angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease) (Stavem et al, 2000). However, even patients with well-controlled seizures report that their condition affects their lives in many ways (Schachter et al, 1993). A diagnosis of epilepsy can bring with it many problems over and above experiencing recurrent seizures. These include stigmatisation, social

isolation, psychological problems and difficulties with education and employment (Buck et al, 1999; Dijibuti & Shakarishvili, 2003; Herodes et al, 2001; Levin et al, 1988). Research exploring the influence of these factors continues to grow.

A number of studies indicate that anxiety and depression are significant predictors of quality of life in epilepsy (Beyenburg et al, 2005; Boylan et al, 2004; Johnson et al, 2004). Au et al (2002) showed that psychosocial variables did make a significantly independent contribution to the prediction of quality of life of patients with epilepsy and also highlighted the importance of the influence of the subjective sense of mastery of the condition on quality of life.

A recent Mexican study (Alanis-Guevara et al, 2005) exploring the factors influencing quality of life indicated that socio-economic factors, sleep disturbance and seizure control were more strongly associated with a lower quality of life than other factors. In this study no association was found with seizure type, aetiology, and duration of disease. Associations of depression symptoms, age and polytherapy with lower quality of life disappeared after a multiple regression was carried out.

1.7.1 Memory & Quality of Life

Patients with resistant epilepsy, the combined effects of the underlying lesion, uncontrolled seizures and the continuous use of antiepileptic drug treatment usually result in impaired neuropsychological functioning that can seriously compromise aspects of quality of life (Moore & Baker, 2002). Some studies suggest that cognitive dysfunction may influence quality of life in epilepsy as much as clinical

variables such as seizure activity, AEDs, and surgery. However, only two studies have looked more specifically at the relationship between memory and quality of life (Giovagnoli & Avanzini, 2000; Perrine et al, 1995). Giovagnoli and Avanzini (2000) attempted to clarify the effect of memory performance on quality of life in-patients with left or right temporal lobe epilepsy. Their main findings were that quality of life was significantly related to both mood and self reported memory in patients with temporal lobe epilepsy. This provided some support for the hypothesis that memory plays a role in determining quality of life in epilepsy. However, the study has a number of methodological limitations. Firstly, it is an Italian study and therefore its findings may not reflect of temporal lobe epilepsy patients in the UK. Secondly, several of the neuropsychological tests and the mood evaluation assessments used have been demonstrated to have lower reliability and validity compared with others used with this patient group. Finally there are also issues arising from multiple testing. The second study investigated the effect of overall impact of cognitive functioning on quality of life in epilepsy patients (Perrine et al, 1995). They demonstrated a close relationship between quality of life and memory abilities in epilepsy but mood and epilepsy related aspects also appeared to be strong predictors of quality of life. In this study, the type of epilepsy syndrome was unspecified and therefore participants potentially had partial and/or generalised seizures originating from different brain areas (other than the temporal lobes). This makes firm conclusions and generalisation to specific groups of epilepsy patient difficult. In addition, executive functioning was somewhat neglected. These results suggested that although seizure control and treatment of depression are vital for enhancing quality of life, memory rehabilitation by specific training might also be effective in

improving daily life in these patients. Conversely, another study found that well-controlled epilepsy patients with late age onset epilepsy of relatively long duration do not report lower health related quality of life. However, when self-reported neuropsychological functioning was explored, difficulties were reported (Engleberts et al, 2002).

There has been limited research exploring the possible link between cognition, and more specifically executive functioning, and quality of life, although a relationship has been indicated by several authors (Engleberts et al, 2002; Perrine et al, 1995; Ringe, 2000; Trimble et al, 1994). A recent paper by Sherman et al (2006) supports a possible link between the two in children with epilepsy. In this study significant executive dysfunction contributed to a twofold increase in the likelihood of poor health related quality of life. Research exploring the impact of various AEDs also lend support to the likelihood of a relationship (Cramer & Van Hammee, 2003; Meador et al, 2001).

1.7.2 Locus of Control, Memory & Quality of Life

Research in other areas, for example in the older adult population, indicates that there is a relationship between locus of control and memory (Verhaeghen et al, 2000; Soederberg et al, 2000). The data indicates that individuals with memory dysfunction are more likely to have an external locus of control. However, there has been a dearth of research in this area in relation to epilepsy. This is surprising given epilepsy's unpredictable nature and the reported frequency of memory problems. A number of studies (for example, Baker & Jacoby, 2002; Preau et al, 2005) suggest

that higher internal locus of control is positively related to health related quality of life in epilepsy and other chronic illnesses such as HIV.

The literature indicates that there is a relationship between locus of control and memory functioning but is vague regarding whether memory affects locus of control or whether locus of control affects memory. Memory functioning may influence the type of locus of control an individual develops, which may subsequently impact on their quality of life. Equally, it might be that locus of control influences memory performance and consequently quality of life.

In order to achieve “true treatment success” we need to understand how individuals perceive their disorder and, where possible, address those factors that adversely affect their quality of life (social, vocational and psychological function). This extends beyond seizure control to freedom from the fear associated with seizures and their consequences, confidence in treatment and improvements in health related quality of life (Sander, 2005).

In summary, further research exploring both the individual and combined influence of memory functioning and locus of control on quality of life in epilepsy is required. The results of this study may have important implications for the assessment of epilepsy patients with memory dysfunction and the implementation of cognitive rehabilitation programs.

1.8 **PRESENT STUDY: AIMS & HYPOTHESES**

- The principal objective of this research is to explore memory functioning and quality of life in individuals with temporal lobe epilepsy.
- Executive functioning in patients with epilepsy of temporal lobe origin will be investigated.
- In addition, the impact of locus of control on memory functioning and quality of life in individuals with temporal lobe epilepsy will be explored.

The following hypotheses were generated:

Hypothesis 1:

In individuals with temporal lobe epilepsy, memory functioning will be positively correlated with quality of life.

Hypothesis 2:

Executive functioning will be positively correlated with quality of life in individuals with temporal lobe epilepsy.

Hypothesis 3:

Memory functioning will be positively correlated with the 'internal' locus of control subscale in individuals with temporal lobe epilepsy.

Hypothesis 4:

Memory functioning will be negatively correlated with the external locus of control subscales ('chance', doctors and 'other people').

Hypothesis 5:

The external locus of control subscales ('chance', 'doctors' and 'other people) will be negatively correlated with quality of life in temporal lobe epilepsy.

CHAPTER 2: METHODOLOGY

CHAPTER 2: METHODOLOGY

2.1 PARTICIPANTS

The Local Research and Ethics Committee and the Research and Development Committee granted approval for data collection to begin (Appendix 1 & 2). Following this, patients diagnosed by neurology as having simple or complex partial seizures of definite or probable temporal lobe origin were identified as potential participants. The local epilepsy nurse identified the majority of these participants and where possible gauged their interest before providing the chief investigator with contact details. A small number of individuals were also identified from the neuropsychology department's database. A number of patients did not opt in however, no reasons for this were provided.

The clinical neuropsychology service covers a large geographical area encompassing Grampian, Shetland and Orkney. Patients with a range neurological disorders (including epilepsy) are seen by the service. The epilepsy nurse fulfils a unique and important role in the delivery of services to people with epilepsy and their carers. In Grampian, 3,619 people (less than one percent) are recorded as having epilepsy (out of the total population of approximately 437,812). Discussions with the epilepsy nurse indicated that the participants approached were fairly representative of the temporal lobe epilepsy population. However, it is important to acknowledge that patients on the epilepsy nurse's caseload are often newly diagnosed or referred due to significant problems arising from their epilepsy.

2.1.1 Inclusion criteria

Patients aged between 18 and 65 years who were diagnosed with epilepsy likely to be of temporal lobe origin were asked if they were willing to take part in the study. The cause of the temporal lobe epilepsy varied from participant to participant. All those approached had experienced at least two recurrent seizures over a 6 month period at some time during the past 5 years.

2.1.2 Exclusion criteria

Individuals deemed incapable under the Adults with Incapacity (Scotland) Act 2000 were excluded from the research. This included individuals with learning disabilities and/or those who were globally impaired as a result of head injury or stroke. Individuals with ongoing alcohol or substance abuse, as set out in the ICD-10 (1990), and individuals with severe complicating psychiatric factors, for example psychosis, were also excluded. In addition, individuals with special communication needs or difficulties understanding verbal or written English were excluded.

2.2 PROCEDURE

All potential patients were sent a letter of invitation, a patient information sheet and a consent form (Appendices 3, 4 & 5). A stamped addressed envelope was included with the pack for return of the consent form. All participants were asked to undergo the same assessment procedure.

The completed consent form was placed in the participant's medical file and two copies were made (one for the patient and one for the chief investigator). Once the

consent forms were returned participants were sent a letter inviting them to attend the neuropsychological assessment (Appendix 6). This included details of when and where the appointment was to be held. Participants were advised to bring glasses for reading if required. Where possible the chief investigator and the epilepsy nurse coordinated their appointments to reduce inconvenience to participants. Arranging appointments within normal working hours was sometimes difficult due to childcare issues and participants' understandable reluctance to take time off work. To overcome these difficulties the chief investigator agreed that affected individuals could be seen out with normal working hours.

The neuropsychological assessment was undertaken at the neuropsychology outpatient clinic. Some participants attended this appointment on their own and others were accompanied by carers and/or significant others. It was emphasised to those accompanying the individual that they should not, at anytime, assist the examinee during the assessment.

Prior to each appointment, the chief investigator explored the patient's medical file for information pertinent to the study. The details were recorded on a pre-prepared form (Appendix 7) and included information regarding gender, handedness, social support, medication (mono or polytherapy), age of onset, and seizure activity (frequency and duration). The information collated was checked with the patient at the beginning of the appointment. Following this, each participant was asked to complete a series of neuropsychological assessments. These explored both their memory and executive functioning. Participants were then asked to complete 3

questionnaires: the Quality of Life in Epilepsy - 31 item questionnaire (Appendix 8), the Multidimensional Health Locus of Control Scale (Appendix 9) and the Hospital Anxiety and Depression Scale. The assessment took approximately 45-60 minutes to complete.

2.3 MEASURES USED

Table 2 summarises the measures used:

Area Assessed	Assessment Used	Source
Memory:		
Verbal Auditory Memory	Logical Memory Subtest	Wechsler, 1997
Visual Memory	Visual Memory Subtest	Wechsler, 1997
Executive Functioning:		
Processing Speed Set Shifting Ability Cognitive Flexibility	Colour Trail Making Test	D'Elia & Satz, 1994
Response Suppression Rule detection & following Set Shifting Ability	Hayling & Brixton	Burgess & Shallice, 1997
Mental Flexibility Multiple Response Generation	Controlled Word Association Test	Benton & Hamsher, 1989; Spreen & Strauss, 1998
Anxiety & Depression	Hospital Anxiety & Depression Scale	Zigmond & Snaith, 1983
Locus of Control	Multidimensional Health Locus of Control Questionnaire	Wallston et al, 1994
Quality of Life	Quality of Life in Epilepsy (Version 1.0)	Perrine, 1993

Table 4: Summary of Assessments

Standard “off-the-shelf” neuropsychological batteries (for example, the Halstead-Reitan Neuropsychological battery) are sensitive to the detection of central nervous dysfunction in a general sense, but lack specificity (Martin et al, 2006). As a result, a flexible battery using number of different subtests and assessments was administered

as opposed to full batteries (Sweet et al, 2006). Working in this way had the additional benefit of reducing the time and effort each participant had to give to the study. A description of each assessment and information regarding reliability and validity is provided below.

2.3.1 Memory Assessment

In this within subject study, two subtests from this Wechsler Memory Scale - Third Edition (WMS-III) were used, namely the visual reproduction and logical memory subtests. The majority of studies exploring cognitive functioning in epilepsy use some or all of these subtests and a number of authors recommend their use in assessing patients with epilepsy (Martin et al, 2006).

The WMS-III was developed from its predecessor, the WMS-R. It is probably the most widely used and most recognisable memory battery for adults (Dori & Chelune, 2004; Butler et al, 1991). It is an individually administered battery of learning, memory and working memory measures and comprises of 11 subtests. Compared with its predecessor, the WMS-III has greatly improved norms, both numerically and in terms of age and ability range. The previous UK version had simply been adapted from the USA test by modifying items that might be confusing or culturally inappropriate for UK population. However, the tests were not standardised on the UK population, nor were there any national studies conducted to check on the appropriateness of the USA norms for this population. The extensive American standardisation project (a stratified, nationally representative sample of 1,250 healthy adults) would have been difficult to replicate and a feasible sample size for the UK

project would not have been large enough to produce reliable and stable norms. Therefore to utilise to fullest extent the large body of US data, it was decided that the UK project would take the form of a validity and comparability study between American norms and scores of a representative sample of the UK population. This was one of, if not the largest, national cognitive data collection exercise ever undertaken with adults in the UK (332 participants made up the final sample). Its overall achievement was to provide sufficient information to allow well-informed use of the USA norms in the UK (Wechsler, 1998).

2.3.1 (a) Logical Memory

Logical Memory is the most frequently administered subtest from the Wechsler Memory Scale (Sullivan, 2005). It is a test of paragraph or prose passage recall (immediate and delayed) in which two short stories are presented orally. The first story was presented once and the second story twice. The examinee was then asked to retell the stories from memory immediately after presentation. Following a delay of approximately 25-35 minutes the participant was again asked to recall the stories. Their recall was scored according to criteria laid out in WMS-III manual. The raw scores were then converted into standard scores for immediate and delayed recall. The Logical Memory subtest is an ecologically valid measure resembling the everyday memory demands found in conversation, the media and written material.

2.3.1 (b) Visual Reproduction

The Visual Reproduction subtest indicates how well an individual can recall visually presented information following both a short and long delay. A series of five designs

was shown, one at a time, for approximately 10 seconds. After each design was presented, the examinee was asked to draw the design from memory. After approximately 25-35 minutes, the examinee was asked to draw the learned designs from memory in any order. Their efforts were scored according to standardised criteria and their raw scores combined and converted into standard scores (one for immediate and one for delayed).

2.3.2 Assessment of Executive Functioning

The following measures explore different aspects of patients executive functioning for example, mental flexibility, inhibition, rule following, processing speed and attention:

2.3.2 (a) Colour Trails Test (CTT) (D'Elia et al, 1996)

This test has been adapted from the Trail Making Test (TMT) (Reitan & Wolfson, 1993). It is said to measure a wide range of abilities (complex visual scanning, motor speed and agility, mental sequencing, sustained visual attention, processing speed and frontal functioning (set shifting and cognitive flexibility). In this study, processing speed and frontal functioning in particular were being investigated.

The CTT was developed in 1990 in response to the World Health Organisation multi centre for HIV infection requesting a similar test to the TMT but with a broader application in cross cultural settings free as possible from the influence of language. This means it can also be used with individuals who have specific language difficulties such as dyslexia. There is an increasing amount of evidence supporting

use the CTT over the TMT (Chan & Lee, 2000; Moses, 2004). Moderate correlations with the TMT parts A and B ($r = .41$ and $.50$) have been demonstrated in adults (Maj et al, 1993).

The CTT uses colour rather than English alphabet letters. Each test has circles printed with vivid pink or yellow backgrounds that are also perceptible to colour blind individuals. There are 2 parts to the test. In part 1 of the test, the respondent was asked to connect circles numbered 1 through to 25 in sequence. This gave an indication of the individuals processing speed and visual attention and tracking abilities. In part 2, the respondent was asked to join numbered circles in sequence, but to alternate between pink and yellow colours. This provided valuable information about participants' cognitive flexibility and set shifting abilities.

2.3.2 (c) Controlled Word Association Test (COWAT)

(Benton & Hamsher, 1976)

The COWAT measures, mental flexibility, multiple response generation, and maintenance of complex task set, intrusion set, perseveration, language ability and use of vulgar or socially inappropriate words. It is widely used by neuropsychologists (Mitrushina et al, 1999) and its reliability and validity are well documented (Lezak, 2004; Spreen & Strauss, 1998). Temporal lobe epilepsy has been associated with deficits on tests of letter fluency (Lezak, 2004).

The COWAT consists of three word naming trials. Norms are provided for letters on the basis of the frequency of English words beginning with these letters. In each set

of three letters, words beginning with the first letter have a relatively high frequency, the second letter has somewhat lower frequency, and the third letter has an even lower frequency. Participants are given a minute to provide as many words they can think of that begin with that letter, excluding proper nouns, numbers and the same word with a different suffix. The score is the sum of all acceptable words produced in the three one minute trials. This score can be adjusted for age, sex and education (Benton et al, 1994).

The associative value of each letter of the alphabet, except X and Z, was determined in a normative study using normal control participants (Borkowski et al, 1967). Control participants of low ability tended to perform less well than brighter brain damaged individuals, highlighting the necessity of taking the patient's premorbid verbal skill level into account when evaluating mental flexibility.

2.3.2 (c) Hayling & Brixton Tests (Burgess & Shallice, 1997)

This assessment has been revealed to be sensitive to the types of problems seen in patients with dysexecutive problems (Burgess & Shallice, 1997). It has been shown to have moderate ecological validity (Odhuba & Broek, 2005).

The Hayling Sentence Completion Test

The Hayling Sentence Completion Test provides a measure of basic task initiation speed as well as performance on a response suppression task. Performance on such tests has been repeatedly associated with dysexecutive symptoms in everyday situations (Burgess, 1997). The Hayling test shows moderate bivariate correlations

with other measures of executive function, including the Six Elements Test (Clark et al, 2000; Marczewski et al, 2001).

Both sections of the Hayling consist of 15 sentences, each missing the last word. These have been adapted from those presented in Bloom and Fischler (1980). In the first section, the participant was asked to complete sentences with the pre-potent response for example, responding as quickly as possible with the word 'ship' when presented with the sentence 'The captain went down with the sinking'. The time taken for them to respond to each item was recorded and converted into a standard score.

In the second section, the subject was asked to suppress the pre-potent response and complete the sentence with a completely unrelated word as quickly as possible for example, giving the response 'door' to complete the sentence 'London is a very busy'. Participants who perform poorly on this task produce answers which either clearly complete the sentences, or that are closely related to semantic aspects of them or take a long time to suppress responses. Higher scoring participants will usually develop strategies to help them deal with the response suppression demands of the task (for example, naming items they can see in the surrounding environment), and nearly all their responses will be unconnected to the sentence.

The number and type of errors and the time taken to respond was recorded. Comparison of the error score and response times in section two may enable a judgement to be made about the style of failure. In other words, impulsive

individuals were either impulsive and responded quickly with errors or were slow in responding but accurate. This task gives three scores, an error score (from section 2) and two measures of response speed (sections one and two). An overall scaled score ranging from 1 (impaired) to 10 (very superior) was used for analysis.

Brixton Spatial Awareness Test

The Brixton Spatial Awareness Task is a rule detection and rule following task. Impairments on such tests are possibly the most commonly demonstrated impairments in people with dysexecutive problems (Anderson et al, 1991; Bondi et al, 1993; Miller, 1992). It is conceptually similar to the Wisconsin Card Sorting Test (WCST) (Heaton, 1981). Indeed, one of its advantages is that it manages to overcome some of the difficulties encountered when using the WCST for example it has been suggested that it is less time consuming and less stressful (Crawford & Henry, 2005). Individuals are asked to uncover the rules regarding the placement of a blue circle among a grid of blank circles. The rule changes when a particular pattern is established. The total errors were recorded and an overall scaled score, ranging from 1 (impaired) to 10 (very superior) was calculated.

The Hayling and Brixton assessments are quickly and easily administered, reducing assessment time and the potential for participants to become fatigued or distressed. They have moderate reliability and moderate specificity and sensitivity (Crawford & Henry, 2005). A recent study indicates that these tests have reasonable ecological validity and that they contribute to understanding the impact of executive functioning on everyday activity (Odhuba & Broek, 2005).

2.4 OTHER AREAS ASSESSED

2.4.1 Hospital Anxiety and Depression Scale (HADS)

(Zigmond and Snaith, 1983)

The HADS is a screening tool originally devised for detecting depression and anxiety in general medical settings. When conducting a neuropsychological assessment with epilepsy patients it is important to include a measure of mood (Perrine et al, 1995). The HADS has been used in several studies of psychological outcome in epilepsy (Jacoby et al, 1996; O'Donoghue et al, 1999) and widely in studies of several other medical conditions, including neurological diseases and cancer. HADS scores have been shown to correlate strongly with other depression rating scales and with psychiatric assessments. Its use has been validated in several studies across various medical and psychiatric conditions (Mensah et al, 2006). This is a useful instrument for use with epilepsy patients as it has fewer items that could potentially be affected directly by epilepsy rather than being true markers of anxiety or depression for example, dizziness and headaches. Good internal consistency for the anxiety and depression subscales has been reported (0.88 and 0.82) for a community epilepsy sample (Jacoby et al, 1996).

This scale is comprised of 14 items, from which two scores are calculated for anxiety and depression. A four-point Likert scoring system is used for each item. Scores range between 0 and 21 for each subscale. Scores of 8 to 10 are obtained by mildly disturbed clients (borderline or 'doubtful cases') and scores of 11 to 21 are likely to indicate definite anxiety and depression. The score considers only negative aspects

of mood and therefore a score of less than 8 cannot be equated with psychological well being.

2.4.2 Quality of life in epilepsy – 31 Item (QOLIE-31)(Version 1.0)

(Cramer et al, 2003; Perrine, 1993)

Several scales have been developed and validated to evaluate quality of life in epilepsy patients. Epilepsy specific scales combine sections of general scales with issues relevant to individuals with epilepsy and have been demonstrated to be more sensitive to change in this population than general scales (Birbeck et al, 2000). The most widely used epilepsy-specific quality of life outcome measures are the Quality of Life in Epilepsy (QOLIE) questionnaires (Privitera & Ficker, 2004). The QOLIE-31 is a survey of health related quality of life for adults (18 years or older) with epilepsy comprising 31 questions about health and daily activities. The QOLIE-31 is a shorter (more efficient) version of the QOLIE-89 and was derived by selecting subscales considered to be most important for epilepsy patients while excluding some general topics (Privitera & Ficker, 2004). It contains seven multi-item scales that tap the following health concepts: emotional wellbeing, social functioning, energy/fatigue, cognitive functioning, seizure worry, medication effects and overall quality of life. One question exploring participants' "health concept" is also included in the inventory but does not contribute to the overall score.

The QOLIE-31 has been shown to have good reliability and validity (Vickrey et al, 1993). Item selection for the QOLIE-31 was based on analysis of data collection from a cohort of 304 adult men and women having different types of seizures of mild

to moderate severity. These patients were enrolled from 25 sites across the United States. All subjects completed a 98-item QOLIE test battery. This was administered to the majority of participants again 3 weeks later. A brief neuropsychological battery, neurological exam, a proxy's assessment of the participants' quality of life and information about seizure occurrence were also obtained (Devinsky et al, 1995; Perrine, 1993). Following data analysis, three measures of quality of life were developed, differing in their number of items: the QOLIE-89, the QOLIE-31 and the QOLIE-10. Internal consistency reliabilities for the multi-item scales ranged from 0.77 to 0.85, exceeding the 0.70 standard for group-level comparisons (Nunally, 1978).

The instrument was scored in accordance with the test manual, with composite scores derived from the subscale scores. A score ranging from 1 to 100 was obtained for each subscale, with higher numbers indicating a higher quality of life.

2.4.3 Multidimensional health locus of control questionnaire (MHLC) (Wallston et al, 1994)

This is widely used to characterise a person's beliefs about control over health outcomes. There are three MHLC scales in all. In this study form C was selected (Wallston et al, 1994). It is designed to be 'condition specific' and can be used in place of forms A and B when studying people with an existing health/medical condition (in this case epilepsy). In common with forms A and B it has 'internal' and 'chance' subscales (of six items each). However, instead of the single six item 'powerful others' subscale, it has two, independent three item subscales: 'doctors'

and 'other people'. For each item, there is a six point agree-disagree response scale. The MHLC's internal reliability has been reported to be in the range of 0.83 to 0.85 (Au et al, 2002). Construct validity was established by a positive correlation between the internal health locus of control and health status, as well as a negative correlation between chance health locus of control and health status (Winefield, 1982).

Four independent scores were calculated, with high scores indicating a strong belief in the subscale locus of control measured.

2.5 ETHICAL CONSIDERATIONS

The local research and ethics board passed this study in February 2007 (Appendix 1).

Some of the key ethical issues considered in this research are outlined below:

2.5.1 Confidentiality

All data will be stored and retained by the Chief Investigator for five years in accordance with research guidelines. Data will be stored according to NHS policies regarding confidentiality in a locked filing cabinet on NHS premises. All data were made anonymous at the initial recruitment stage, with each consenting individuals assigned a number used to identify them thereafter. Information will be stored on the computer in this form. The list of identification numbers and participant consent forms will be kept in a locked cabinet in the department of clinical neuropsychology.

2.5.2 Distress during Assessment

It was not anticipated that this investigation would cause any distress to participants. However, it was made clear that in the unlikely event that participants reacted in an unexpected way and/or became upset the assessment would be stopped. In addition, the participants had the chief investigator's contact details and it was made clear that they could contact her if they had any concerns regarding their participation.

2.5.3. Capacity Issues

It was foreseen that there might have been issues in relation to an individual's capacity to consent to participate in this research. It was therefore agreed that if there was any doubt regarding an individual's ability to consent they would be excluded.

2.5.4 Other Ethical Issues

It was possible that assessment might reveal severe general or more specific cognitive and/or psychological dysfunction (clinical significant anxiety or depression) not previously revealed. If this occurred it was agreed that the chief investigator would discuss sharing this information with the epilepsy nurse. Suicidal ideation might also have been discovered. If this occurred it was agreed that the on-call psychiatrist would be contacted as soon as possible.

2.6 DATA ANALYSIS

Only 2 studies explored related comparisons in this area and one of these did not report effect size and/or means and standard deviations from which effect sizes could



be calculated (Giovagnoli and Avanzini, 2000). However, the paper by Perrine et al (1995) explored the relationship of neuropsychological functioning to quality of life in epilepsy and reported a significant correlation with memory ($r=.42$). This finding combined with a power analysis table from the following website give an approximate estimate of the required N for this study: <http://www.rowett.ac.uk/~gwh/corr.html>. In this case a minimum of approximately 35 participants was required for required significance levels ($\alpha = 0.50$ and power = 0.80).

The Kolmogorov-smirnov test was conducted on the data. This showed that the data was normally distributed and therefore justified the use of parametric tests. A parametric test is one, which is based on certain assumptions about the properties of the population from which samples are taken. All statistical analyses were run using SPSS Version for Windows. Pearson correlations were used to investigate relationships between variables.

The number of correlations to be conducted increased the risk of type 1 error i.e. the risk of stating that a result is significant when it is not. This suggests that if one conducted an experiment using random data, 1 in 20 times (on average) a result at the 5% level would be found. To reduce this risk a p value of < 0.01 was adopted.

CHAPTER 3: RESULTS

CHAPTER 3: RESULTS

3.1 BACKGROUND INFORMATION

3.1.1 Participants

Of the 44 patients who were approached, 22 opted into the study giving an overall response rate of 50%. All those who opted in were included in the study and there was no missing data. The age of participants ranged from 22 to 60 years of age (mean = 41.3 years; sd = 9.8 years) and the age range of those who did not respond ranged from 17 to 64 years (mean = 34.4 years; sd = 12.1 years). Table 5 summarises the gender and age groups of those who opted in and those who did not.

	Gender		Age				
	Male	Female	18-29	30-39	40-49	50-59	60-65
Participants	12	10	2	8	6	5	1
(%)	(54.6%)	(45.4%)	(9.1%)	(36.4%)	(27.3%)	(22.7%)	(4.5%)
No Response (%)	7	15	9	8	3	1	1
	(31.8%)	(68.2%)	(40.9%)	(36.4%)	(13.7%)	(4.5%)	(4.5%)

Table 5: Gender & Age Groups of Participants & Individuals who Did Not Respond

Table 6 shows the deprivation category which the participants and those who did not respond were likely to belong to. This was calculated using the Carstairs and Morris index of social deprivation. This index allows one to calculate levels social deprivation according to postcode sectors and 2001 census data. The deprivation score is divided into 7 categories ranging from very low (1) to very high social deprivation (7).

	Carstairs & Morris Deprivation Category						
	1	2	3	4	5	6	7
Opted In (%)	4 (18.2%)	7 (31.8%)	6 (27.3%)	5 (22.7%)	0	0	0
No Response (%)	5 (22.7%)	2 (9.1%)	3 (13.7%)	7 (31.8%)	1 (4.5%)	4 (18.2%)	0

Table 6: Carstairs & Morris Index of Deprivation Score

All of the participants were right-handed. Eighteen (81.8%) reported that they were ‘satisfied’ or ‘very satisfied’ with the support they received from their family and friends. However, several participants (including 5 participants who stated they were ‘satisfied or very satisfied’) commented that people often “misunderstood” their epilepsy and one participant mentioned their “continuous battle against old fashioned views”. One individual (4.5%) commented on how their employers and family were sometimes “overprotective” and another confessed that they had kept their diagnosis from the majority of their friends and family and from their work colleagues.

3.1.2 Seizure Activity (Cause, Onset, Frequency)

The majority of participants (16 or 71.7%) had temporal lobe epilepsy of ‘cause unknown’. Five of the participants (22.7%) developed temporal lobe epilepsy as a result of congenital malformation and one individual (4.5%) had developed it following a brain haemorrhage. Nine (40.9%) had received their diagnosis over ten years ago, two (9.1%) between 5-10 years ago and ten (45.5%) had received their diagnosis sometime over the past five years. Only one individual (4.5%) had been diagnosed in the past year. Sixteen participants (72.7%) had experienced at least one seizure in the past 6 months and five (22.7%) of these had experienced seizures sometime within the week preceding the assessment. When discussing seizure

activity, a number of participants mentioned both their fear of having seizures and the potential repercussions. They were particularly concerned about the impact seizure activity might have on their independence and employment prospects.

3.1.3 Employment Issues

Thirteen (59%) of the participants were employed full-time, four (18.2%) part-time and five (22.7%) were unemployed. They were involved in a range of occupations including engineering, teaching, employment within the sales and service sector. All those who were unemployed commented that they had been forced to stop working due to their epilepsy and four (18.2%) of those in full time employment had either changed careers or altered their jobs to meet the challenges posed by this condition. Five (22.7%) were self-employed.

3.1.4 Anti Epileptic Drugs (AEDs)

Thirteen participants (63.6%) were on a monotherapy regime and eight (36.4%) were on a polytherapy course of AEDs. The main AEDs prescribed to the participants included Epilim, Tegretol, Keppra, Lamotrigine, and Carbamazepine.

3.1.5 Psychological Functioning

The Hospital Anxiety and Depression Scale (HADS) was administered to determine whether participants may have had significant anxiety and/or depression. The overall mean for anxiety (mean = 8.1; sd = 3.8) was higher than the mean for depression (mean = 4.5; sd = 3.3). Figure 2 shows participants' scores (with cut off for clinical significance). Eight (36.7%) individuals scored above the cut off for

clinically significant anxiety (merits further psychiatric assessment). Six participants (27.3%) scored within the mildly depressed range (considered ‘doubtful cases’) but no one presented with above the cut off for clinically significant depression.

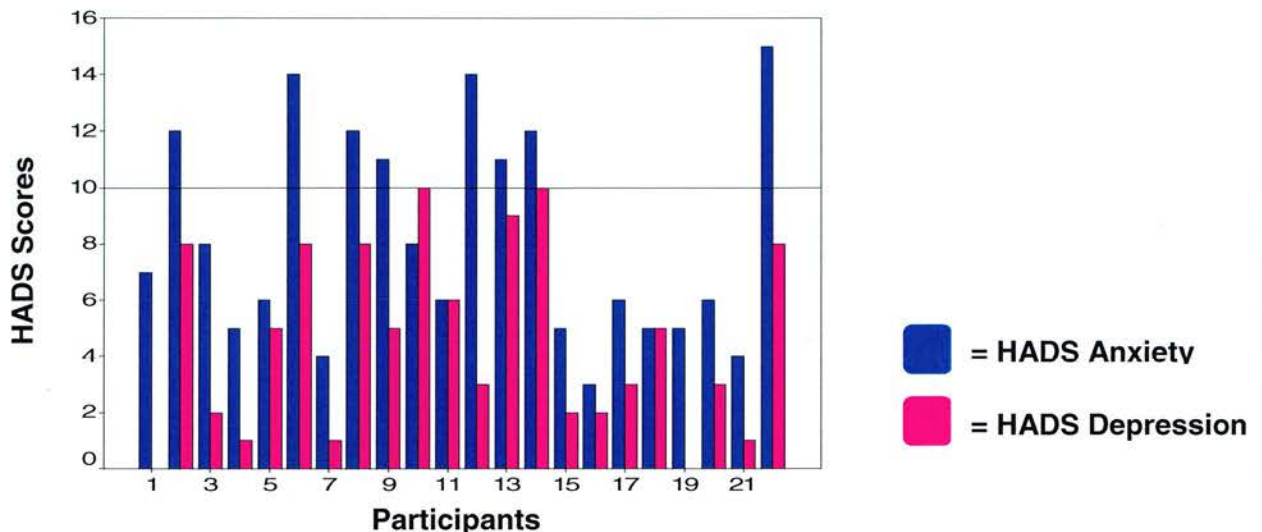


Figure 2: Participants' HADS Scores

3.2 EXPLORATION OF HYPOTHESES

3.2.1 Hypothesis 1:

In individuals with temporal lobe epilepsy, memory functioning will be positively correlated with quality of life.

Overall, there was considerable variation in the sample's performance on verbal and visual memory (immediate and delayed). Five (22.7%) participants performed within the moderate to severely impaired range on both immediate verbal and visual memory. One (4.5%) participant displayed severe difficulties with immediate verbal memory but had average immediate verbal memory. After a delay, six participants (27.3%) displayed moderate to severe difficulties in both tasks. One participant

(4.5%) presented with significant difficulties in verbal memory and one (4.5%) had difficulties with visual memory only.

Figure 3 shows the overall quality of life score for each participant and demonstrates variability across the sample. An overall quality of score ranging from 1 to 100 was obtained with higher numbers indicating a higher quality of life. The mean average score for the general population has been calculated at 62.87 (sd = 16.31). The overall quality of life mean for all those assessed was 56.2 (sd = 20.4).

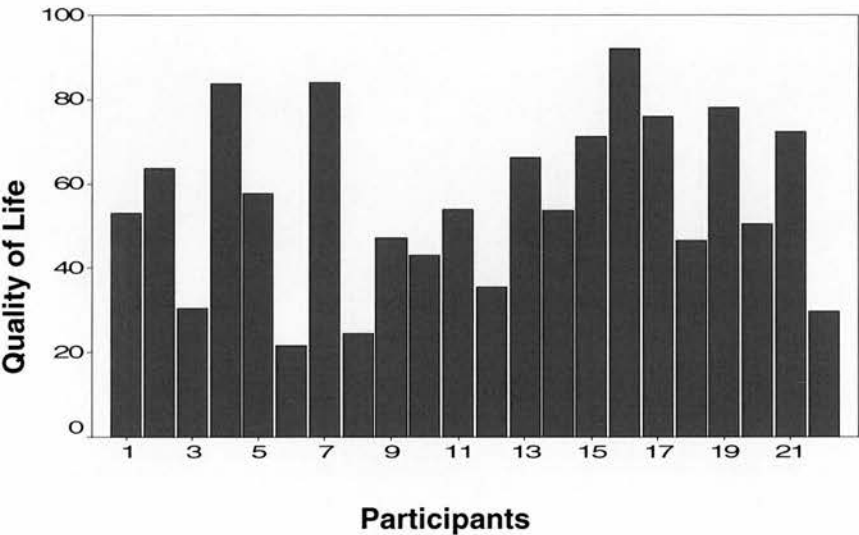


Figure 3: Participants’ Quality of Life Scores

Pearson correlations did not reveal a significant positive relationship between immediate verbal memory and quality of life ($r = 0.41$, $n = 22$, $p = .030$, one-tailed) but did reveal a significant relationship between immediate visual memory and quality of life ($r = 0.60$, $n = 22$, $p < .001$, one-tailed).

A positive correlation between delayed verbal memory and quality of life was revealed ($r = 0.45$, $n = 22$, $p = .018$, one-tailed) but this was not significant at $p < .01$. A positive correlation was revealed between performance on delayed visual memory and quality of life ($r = 0.61$, $n = 22$, $p < .001$, one-tailed). The correlation with delayed visual memory is displayed in Figure 4:

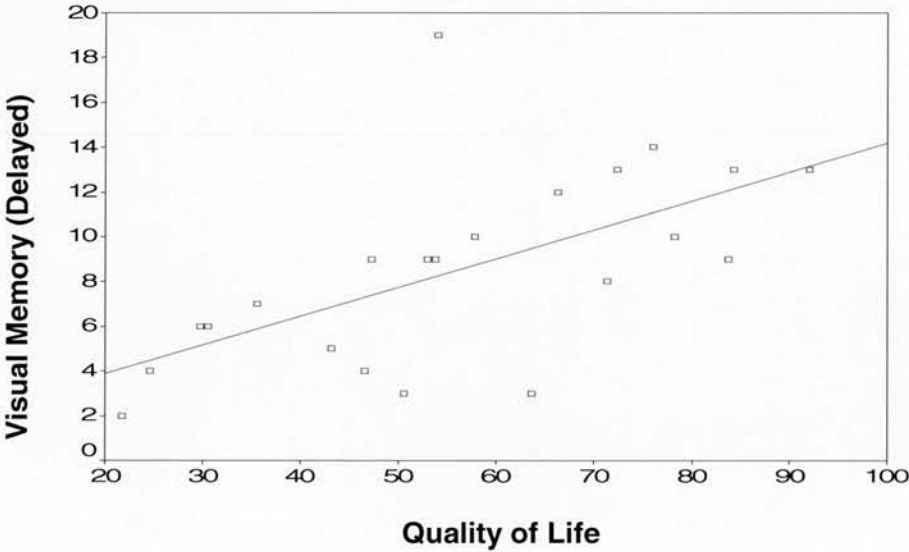


Figure 4: Delayed Visual Memory & Quality of Life

3.2.2 Hypothesis 2:

Executive Functioning will be positively correlated with quality of life in individuals with temporal lobe epilepsy.

Different aspects of executive functioning were explored using five executive functioning assessments. Overall, participants demonstrated relative strengths and weaknesses in executive functioning. Participants performed less well on the sustained attention (Colour Trails part 1) and the Hayling and Brixton Tests. Six (27.3%) scored below average on the Colour Trails Test 1. Nine (40.9%) displayed

significant difficulties on the Hayling Sentence Completion Task and six (27.3%) displayed significant difficulties on the Brixton Sentence Completion Task. Participants did not present with significant difficulties with the Controlled Word Association Test (COWAT) or Colour Trails 2 and Pearson correlation revealed that these three tasks were not significantly associated with overall quality of life. The results of the Pearson correlations between the executive functioning tasks and quality of life are summarised in Table 7. Controlling for memory did not impact greatly on the correlations revealed.

		N	Quality of Life
Trails 1	Pearson Correlation (1-tailed)	22	$r = 0.54$ $p < .005$
Trails 2	Pearson Correlation (1-tailed)	22	$r = 0.30$ $p = .089$ NS
COWAT	Pearson Correlation (1-tailed)	22	$r = 0.28$ $p = .102$ NS
Hayling	Pearson Correlation (1-tailed)	22	$r = 0.58$ $p = .002$
Brixton	Pearson Correlation (1-tailed)	22	$r = 0.50$ $p = .009$

Table 7: Correlations between Executive Functioning Tasks & Quality of Life

Pearson correlations showed a positive correlations between quality of life and performance on the Colour Trails part 1 ($r = 0.54$, $n = 22$, $p < .005$, one-tailed), the Hayling Sentence Completion Test, ($r = 0.58$, $n = 22$, $p = .002$, one-tailed) and the Brixton Test ($r = 0.50$, $n = 22$, $p = .009$, one-tailed).

3.2.3 Hypothesis 3:

Memory functioning will be positively correlated with the ‘internal’ locus of control subscale in individuals with temporal lobe epilepsy.

The ‘internal’ subscale from the Multidimensional Health Locus of Control Scale did not show a significant correlation with either the immediate verbal memory score ($r = -0.34$, $n = 22$, $p = .062$, one-tailed) or the delayed verbal memory score ($r = -0.23$, $n = 22$, $p = .152$, one-tailed). No correlation was revealed between either the immediate ($r = -0.43$, $n = 22$, $p = .024$, one-tailed) or delayed visual memory ($r = -0.16$, $n = 22$, $p = .239$, one-tailed) and the ‘internal’ locus of control subscale.

3.2.5 Hypothesis 4:

Memory functioning will be negatively correlated with the external locus of control subscales (‘chance’, doctors and ‘other people’) in individuals with temporal lobe epilepsy.

Pearson correlations revealed significant negative relationships between immediate verbal memory and two of the external locus of control scales (‘chance’ and ‘other people’). No relationship was found between immediate visual memory and ‘chance’ or ‘doctors’ but a significant negative correlation was revealed between immediate visual memory and ‘other people’ ($r = -0.53$, $n = 22$, $p = .005$, one-tailed). The results of these correlations are shown in Table 8.

		N	Verbal Memory Immediate	Visual Memory Immediate
Chance	Pearson Correlation (1-tailed)	22	$r = -0.53$ $p = .005$	$r = -.031$ $p = .078$ NS
Doctors	Pearson Correlation (1-tailed)	22	$r = -0.38$ $p = .039$ NS	$r = -0.03$ $p = .450$ NS
Other People	Pearson Correlation (1-tailed)	22	$r = -0.50$ $p = .009$	$r = -0.57$ $p = .003$

Table 8: Correlations between Immediate Memory (Visual & Verbal) & External Locus of Control Subscales

Significant negative relationships were revealed between delayed verbal memory and the ‘other people’ subscale ($r = -0.67$, $n = 22$, $p < .001$, one-tailed). No significant relationships were revealed between delayed verbal memory and the ‘chance’ and ‘doctors’ subscales. Delayed visual memory only correlated with the ‘other people’ subscale ($r = -0.53$, $n = 22$, $p = .005$, one-tailed). The results of these correlations are shown in Table 9.

		N	Verbal Memory Delayed	Visual Memory Delayed
Chance	Pearson Correlation (1-tailed)	22	r = -0.44 p = .022 NS	r = -.018 p = .209 NS
Doctors	Pearson Correlation (1-tailed)	22	r = -0.47 p = .013 NS	r = -0.03 p = .450 NS
Other People	Pearson Correlation (1-tailed)	22	r = -0.67 p < .001	r = -.053 p = .005

Table 9: Correlations between Delayed Memory (Visual & Verbal) & External Locus of Control Subscales

3.2.6 Hypothesis 5:

The external locus of control subscales ('chance', 'doctors' and 'other people') will be negatively correlated with quality of life in temporal lobe epilepsy.

Pearson correlations did not reveal any significant relationships between the external locus of control subscales and quality of life in temporal lobe epilepsy. These results are summarised in Table 10.

		N	Quality of Life
Chance	Pearson Correlation (1-tailed)	22	$r = -0.14$ $p = .268$ NS
Doctors	Pearson Correlation (1-tailed)	22	$r = -0.05$ $p = .419$ NS
Other People	Pearson Correlation (1-tailed)	22	$r = 0.34$ $p = .064$ NS

Table 10: Correlations between Multidimensional Health Locus of Control External Subscales & Quality of Life

3.3 OUTLIERS

During statistical analysis there were a number of outliers identified. Each of these outliers was explored, but as there were no reasons to suppose that they were not valid data, they were included in analyses. The individuals identified were revealed to be either very high or very low functioning individuals.

CHAPTER 4: DISCUSSION

CHAPTER 4: DISCUSSION

This study aimed to investigate whether individuals with temporal lobe epilepsy and difficulties with their memory functioning experience lower quality of life. The impact of executive functioning and locus of control on memory and quality of life in temporal lobe epilepsy was also explored. It was suggested that these two variables exerted a significant influence on the main research question posed. Participants underwent a battery of neuropsychological assessments and completed questionnaires assessing locus of control, quality of life and psychological functioning.

The main findings of this study are presented and discussed in relation to each of the hypotheses put forward in the introduction. The theoretical and clinical implications of these results are considered. Finally, the methodology of this study is evaluated and suggestions for further research proposed.

4.1 GENERAL ISSUES

Initially participants were asked for background information regarding their epilepsy. The key issues arising from this are discussed below.

There were over twice as many females than males in the group that did not respond to the invitation to participate. The majority of all these individuals were within the 18-39 years age range. In addition, over half of this group had a social deprivation score of four or more compared with those who opted in, of whom the majority

scored within the less deprived categories (categories 1-3). As a result of the latter point, individuals who did not respond were more likely to have had more financial limitations compared with the majority of the participants. These limitations could potentially have meant that time off from employment, additional childcare costs and access to transport made participation difficult.

The majority of participants' epilepsy was of 'cause unknown'. This figure is in keeping with previous studies which indicate that 60-70% of epilepsies are of unknown aetiology (Sander, 2003). All except one of the participants had experienced seizures in the past six months and a small number had experienced seizures in the week preceding the assessment. Almost half the sample had been given their diagnosis more than 10 years ago and a number had been given their diagnosis in childhood. This was interesting given the evidence which suggested that the duration epilepsy is positively correlated with the degree of neurocognitive dysfunction exhibited (Strauss et al, 1995). Almost half of the participants were on a polytherapy regime of antiepileptic medication. This was unsurprising given that the epilepsy nurse was the main source of research participants and often sees people with uncontrolled epilepsy.

Fear of seizures and concerns about the consequences and functional limitations of the seizures themselves were raised (for example, the social and financial implications of being unable to drive). Comments made about the misunderstandings that can occur and the social stigma people feel were unsurprising given the history of this condition and the reports of many working in the field

(Shafer, 2002). The reactions given and the support and encouragement provided by significant others has been highlighted as key in helping individuals to cope and adjust to epilepsy and this seemed to be the case for many of the participants in this study. An accurate understanding of epilepsy is vital in facilitating this adjustment, as is containment of anxiety (Usiskin, 2005). Conversely in some situations, families and/or significant others can become too involved and overprotective and there is a risk that this may lead to illness behaviour and increased dependency (Usisikin, 2005). Providing education and support could potentially help dispel the myths and misconceptions surrounding the epilepsy, reduce the emotional impact of seizures, improve both individuals and their family' adjustment to epilepsy and ultimately improve quality of life (Gupta & Naorem, 2003). Education of wider society might also be an issue to consider when attempting to overcome the stigma often attached to this condition. This might include speaking to a variety of different groups in society such as politicians and school children.

The majority of those in the sample were employed. However, exploration of participants' comments revealed that many faced daily challenges at work as a result of their epilepsy. The challenges identified included fear of seizures, social stigma and cognitive difficulties. A significant number were self-employed and several commented that they had been denied their preferred occupation or had been compelled to adapt their employment as a result of their epilepsy. Work has many functions aside from financial reward. It provides a way of structuring time, and more importantly, contributes to a person's identity and feelings of self-worth (Thompson & O'Toole, 2005). For many people with epilepsy, employment

presents as a major quality of life issue and unemployment can potentially contribute to the increased psychopathology often observed in epilepsy (Baker, 2005).

None of the participants scored highly on the depression measure. This may reflect a selection bias, as significantly depressed individuals may not have opted into this research due to lack of motivation and lethargy, common symptoms of depression. Higher levels of anxiety were revealed in the sample. This is in keeping with the literature which highlights the prevalence of anxiety in epilepsy (Beyenburg et al, 2005; Vazquez & Devinsky, 2003).

When considering these results, the impact of anxiety had to be taken into account. High levels of anxiety have been shown to adversely affect performance on many different kinds of mental ability tests (Lezak et al, 2004). A number of participants were shown to have clinically significant anxiety and it is possible that this impacted on their performance, especially on the memory tasks. Unlike executive functioning tasks, participants are more likely to notice when memory is being assessed due to the nature of the test material used and this may affect their performance.

4.2 HYPOTHESES

4.2.1 Hypothesis 1:

In individuals with temporal lobe epilepsy memory functioning will be positively correlated with quality of life.

A positive correlation was revealed between both verbal and visual memory (immediate and delayed) and quality of life, although only visual memory of was

significant at the $p < .01$ level. These findings lend support to the hypothesis and indicate that individuals with temporal lobe epilepsy and average or above average memory will tend to report higher quality of life than individuals with temporal lobe epilepsy who experience memory problems. However, it is difficult to know if this relationship is more pronounced in epilepsy, or whether memory and quality of life would be equally correlated with other clinical groups (for example, those with traumatic brain injury or multiple sclerosis) or with non-memory impaired groups.

There is a dearth of literature exploring quality of life and memory in epilepsy generally and more specifically in temporal lobe epilepsy. Current research indicates that memory and cognitive abilities are predictive of quality of life (Giovagnoli et al, 1999; Perrine et al, 1995; Trimble et al, 1994). Research with other patient groups for example, those who have sustained a brain injury, older people and schizophrenic patients, lends support to these findings (Hawley, 2006; McDermid et al, 2002). Work conducted by LoGiudice et al (1999) demonstrates that the quality of life of carers is also influenced by memory problems. The findings of the present study are consistent with the available literature in this area and highlight the potentially significant impact that memory functioning can have on quality of life. Difficulties in recalling information may influence many different aspects of life including activities of daily living (personal care, housework), social interactions and employment.

These results go some way to support the view that conducting neuropsychological assessment with individuals who have temporal lobe epilepsy is important.

Neuropsychological assessment highlights potential problems, provides useful information regarding an individual's cognitive strengths and weaknesses and provides a valuable baseline against which future assessments can be measured. This information can be used to improve the individual's psychological well being and quality of life. The role clinical neuropsychology can play in both the assessment and treatment of cognitive dysfunction in epilepsy process is being increasingly recognised in health service documents for example, in the NICE Guidelines on Epilepsy. Ideally all newly diagnosed patients with epilepsy should undergo a brief neuropsychological screen prior to starting treatment (Baxendale, 2005). In addition, due to the valuable information it provides about the individual's cognitive profile, neuropsychological assessment is seen as a prerequisite for planning and implementing individually tailored cognitive rehabilitation programmes which have been shown to improve an individual's functioning in 'real life' contexts (Gupta & Naorem, 2003).

The results of this study coupled with the above research indicate that methods to ameliorate memory problems might improve the quality of life of individuals with temporal lobe epilepsy. However, there is a lack of empirical research to guide the treatment of memory dysfunction in epilepsy. Cognitive dysfunction is usually managed indirectly with aggressive seizure control, selection of antiepileptic drugs shown to have fewer cognitive side effects, and treatment of co-morbid depression and/or anxiety (Shulman & Barr, 2002).

In recent years, cognitive rehabilitation has been the focus of much attention in neuropsychology. However, most of the research in this area takes the form of case studies or non-controlled small studies and randomised control trials are scarce (Ponds & Hendriks, 2006). In addition, very few studies have investigated cognitive rehabilitation for memory difficulties in epilepsy specifically. Particular factors have been identified as important when considering memory difficulties in epilepsy. The severity and frequency of seizures, seizure site, antiepileptic medication, surgery, mood and age on onset have all been shown to influence memory functioning (Thomson, 1997). The chronic nature of epilepsy increases the likelihood that memory problems will appear and increase over time and this may reduce the individual's quality of life (Ponds & Hendriks, 2006).

A number of suggestions have been put forward regarding the most effective way to design memory rehabilitation programs for individuals with epilepsy (Aldenkamp & Vermeulen, 1991). The key points made in relation to this include: goal planning for the individual, relating strategies to everyday contexts; psycho education; considering the impact of personality and emotional reactions and exploring the individual's perception of their memory problems (Ponds & Hendriks, 2006). Gupta and Naorem (2003) stress the need to establish more effective remedial programmes for the deficits in cognitive functioning associated with epilepsy and are of the opinion that these would be "of substantial benefit" to this client group. They present a case study that describes a six-session cognitive rehabilitation programme combined with regular home intervention sessions. The strategies taught involved helping their patient to organise information more effectively to aid their memory for

example, chunking and categorising information and using imagery. The individual demonstrated good use of the taught strategies and an improved emotional and behavioural state following this intervention.

4.2.2 Hypothesis 2:

Executive Functioning will be positively correlated with quality of life in individuals with temporal lobe epilepsy.

Moderate positive relationships were revealed between three of the executive functioning tasks and quality of life. These tasks included the Colour Trails part 1 and the Hayling and Brixton tests. No significant relationships were revealed between quality of life and the Controlled Word Association Test or the Colour Trails part 2. These findings provide partial support for the above hypothesis. In this study the executive functioning measures were still significantly correlated with quality of life when memory was controlled for and vice versa.

The correlation discovered between quality of life and the Colour Trails part 1 (which assesses processing speed and sustained attention) is interesting, especially given that no correlation was revealed between the more difficult Colour Trails 2 (divided attention and set-shifting task) and quality of life. Issues with sustained attention in epilepsy have been raised and some go so far as to suggest that it is more significant in predicting academic failure than memory or socio-economic factors (Sanchez-Carpintero, 2003; Van Rijkevorsel, 2006). Reduced processing speed is also often found in patients with epilepsy (Engleberts et al 2002) and several papers suggest that this is a frequent side effect of antiepileptic medication (Dodrill 1988;

Meador, 2001). There is some evidence to indicate that temporal lobe epilepsy patients with reduced white matter volumes exhibit impaired information processing speed performance on the Wisconsin Card Sorting Test compared with both temporal lobe epilepsy patients with normal white matter volume and healthy controls (Dow et al, 2004).

Consideration should be given to the potential influence of sustained attention on memory processing. If an individual does not attend to information it will not be encoded sufficiently for later recall. Given the results revealed in relation to hypothesis one, such memory deficits are likely to have a 'knock on' effect on quality of life.

Almost half of the individuals' assessed demonstrated difficulties on the Hayling Sentence Completion Task suggesting that they had difficulties with basic task initiation speed and response suppression and just over 25% demonstrated significant difficulties on the Brixton Spatial Awareness Task. Both of these tasks correlated with quality of life. These results support the increasing evidence which indicates that executive dysfunction is present in temporal lobe epilepsy and is particularly noticeable in higher multilevel executive tasks (Bougakov, 2005; McDonald et al, 2005).

Performance on executive functioning tasks has been repeatedly associated with dysexecutive symptoms in everyday situations. Executive dysfunction may manifest itself as 'odd' or unusual behaviour which can be challenging for those who are part

of an individual's support network and can impact on the individual's quality of life. Such behaviour may be misinterpreted due to a lack of understanding or awareness and could potentially lead to social isolation and stress. Executive dysfunction may also present more subtly and only become apparent in high level executive tasks, which are more often encountered in work settings. Such difficulties may have significant implications for individuals whose work makes such cognitive demands (Ringe, 2000).

Several papers point to the existence of a relationship between cognition, executive functioning and quality of life in epilepsy (Engleberts et al, 2002; Perrine et al, 1995; Ringe, 2000; Trimble, 1994). A more recent paper demonstrates that executive dysfunction is a significant predictor of quality of life in children with epilepsy (Sherman, 2006). Evidence from other areas, for example research conducted with patients who have severe and enduring mental illness, also reveal that executive functioning is predictive of quality of life issues such as family contact and financial support (Fujii et al, 2004).

No correlation was found between the set shifting, mental flexibility and quality of life. The evidence for the presence of these difficulties in epilepsy is limited and inconsistent. It may be that set shifting and mental flexibility are less of an issue than the other areas of executive functioning in relation to everyday functioning and quality of life. Alternatively, set shifting and mental flexibility may not have been directly related to self-perceived functional daily activities or well being as assessed by the quality of life measure. This does not necessarily mean they can be ignored.

In addition, the Hayling and Brixton tests have been shown to have reasonable ecological validity (Crawford & Henry, 2005) whereas the ecological validity of the Controlled Word Association test has been questioned (White, 2005).

These results suggest that efforts to improve quality of life in epilepsy might include interventions for executive dysfunction possibly similar to the cognitive rehabilitation programmes used to help patients with memory problems. However the question of whether executive dysfunction can be effectively treated remains unanswered. Conclusions drawn from a review of the literature are “cautiously positive” but many issues remain (Evans, 2005). Executive functions are poorly defined and theoretical irregularities makes evaluation of rehabilitation studies difficult and this has probably limited the number of studies undertaken. Some of the most persuasive work addressing rehabilitation of executive functions has been done with individuals who have a diagnosis of schizophrenia (Penades et al, 2006; Silverstein et al, 2004). Overall, substantially more high quality research is needed to determine whether specific aspects of executive functioning can be improved through tailored interventions in individuals with temporal lobe epilepsy. As is the case with cognitive rehabilitation for memory dysfunction, comprehensive assessment of executive functioning will be required when planning any interventions (Crawford & Henry, 2005).

Generally existing research supports the notion that cognitive abilities (memory and executive functioning), as perceived by the patient and assessed by formal testing,

impact significantly on everyday functioning and quality of life (Perrine et al, 1995). These findings reinforce this view. However, executive dysfunction in temporal lobe epilepsy is often overshadowed by the more commonly reported memory difficulties. Those working with individuals with temporal lobe epilepsy must be mindful of its potential influence not just in the lab but also in 'real world'.

4.2.3 Hypothesis 3:

Memory functioning will be positively correlated with the 'internal' locus of control subscale in individuals with temporal lobe epilepsy.

No relationship was revealed between verbal memory (immediate and delayed) and the 'internal' locus of control subscale or between visual memory (immediate and delayed) and the 'internal' locus of control subscale. Overall, these findings do not support the hypothesis.

The author proposed that difficulties in memory functioning resulting from temporal lobe epilepsy might cause individuals to become increasingly more reliant on others for assistance and consequently less independent. It was suggested that this might cause individuals to develop the belief that they had little personal control over their epilepsy. This assumption was based on information from the literature which suggested a potential relationship between internal locus of control and memory dysfunction in epilepsy and other chronic illnesses (Baker & Jacoby, 2002; Preue et al, 2005). However, in this study, memory difficulties did not lead people with temporal lobe epilepsy to perceive they had less personal control over their epilepsy. It may be that other factors are more important in influencing feelings of internal

control, for example there is substantial evidence pointing to the role of depression in decreasing internal locus of control. The finding that participants did not appear to have significant levels of depression would support this possibility.

4.2.4 Hypothesis 4:

Memory functioning will be negatively correlated with the external locus of control subscales ('chance', doctors and 'other people') in individuals with temporal lobe epilepsy.

Analysis of data revealed significant negative relationships between verbal memory (immediate and delayed) and the two of the three external subscales ('other people' and 'chance'). Visual memory was shown to correlate significantly with the 'other people' subscale only. These findings provide only partial support for the above hypothesis, at least in relation to verbal memory. They indicate that memory dysfunction in temporal lobe epilepsy potentially increases the possibility of individuals believing that chance and significant others play an important role in how their epilepsy behaves.

Those with significant memory dysfunction are more likely to have intractable epilepsy with frequent seizure activity. As a result of this, individuals will be in more regular contact with doctors and other health professionals as efforts continue to bring their epilepsy under control. These people are also more likely to require higher levels of support from their family and friends to help them adapt and cope with the challenges posed by their epilepsy. Good social support may help contribute to the self-management of the epilepsy, including the use of cognitive

strategies, and may help to moderate the effects of social stigmatisation (Dilorio et al, 1992). The importance of good social support in predicting of quality of life in this condition has been highlighted (Au et al, 2002).

These results support the view that the involvement of significant others in the treatment and management of epilepsy is important. They also support the usefulness of empowering patients themselves to take action to minimise the impact epilepsy can have on everyday life. The cognitive rehabilitation programmes and strategies referred to previously may offer some solutions and assist in helping people feel more in control where memory functioning is an issue. Unfortunately, there is little high quality research exploring interventions that might help people with epilepsy self-manage and ameliorate some of the negative effects of epilepsy. In addition, the majority of this work to date tends to describe the issues but fails to come up with solutions (Baker & Moore, 2002).

A strong belief in the influence of chance may decrease a person's own feelings of personal control over their epilepsy. Both the ever-present threat and uncertainty about when the next attack will occur have been shown to leave individuals feeling isolated and misunderstood. It is likely that memory dysfunction will exacerbate this uncertainty and unpredictability and potentially increase the likelihood of chance being seen as significant. Difficulty recalling information can result in increased anxiety and frustration and reduced self confidence. This has potential repercussions for an individual's mental health which may result in a rather clandestine type of existence (Usiskin, 2005).

4.2.5 Hypothesis 5:

The external locus of control subscales ('chance', 'doctors' and 'other people') will be negatively correlated with quality of life in temporal lobe epilepsy.

No significant correlations were revealed between the external locus of control subscales and quality of life. These findings do not support the above hypothesis.

It was inferred that individuals with higher scores on these subscales would report lower quality of life. This inference was based on literature which indicated that higher scores on external locus of control measures are associated with depression, and negative consequences of epilepsy such as perceived severity and social stigma (De Villis et al, 1986). More specifically the influence of self-efficacy in the prediction of health related quality of life in epilepsy has been found by several authors (Amir et al, 1999; Au et al, 2002). Participants from the Au et al (2002) study who believed their health condition was significantly a matter of chance reported poorer quality of life.

There are a number of possible reasons why no relationship was revealed between these two variables. It may be that many individuals, particularly those who have had epilepsy for many years, adopt a more stoical view of their epilepsy and accept whatever challenges it presents them with. They are focused on living their lives despite these hurdles. In addition, it may be that doctors and other people actually provide some protection against reported lower quality of life. This would relate to

the literature which stresses the value of support from significant others in maintaining stable psychological well being and quality of life.

4.3 CONCLUSIONS

This research provided support for the hypotheses 1 and 2. Overall memory and executive functioning correlated with both quality of life in individuals with temporal lobe epilepsy. Hypothesis 4 received some partial support but there was no evidence to support hypotheses 3 and 5. A number of correlations were revealed between memory and the 'chance' and 'other people' subscales. However, memory functioning did not correlate with the 'internal' locus of control subscale and the external locus of control scales did not correlate with quality of life in temporal lobe epilepsy.

The key findings and their potential implications as follows:

- Cognitive dysfunction (memory and executive dysfunction) in individuals with temporal epilepsy can significantly disrupt quality of life.
- Neuropsychological assessment could potentially provide useful information regarding the individual's cognitive strengths and weaknesses. This can be used to monitor changes in cognition and to inform treatment.
- Improved quality of life should be viewed as an important outcome of successful treatment.

- The results of this study would indicate that intervention for cognitive dysfunction is important (due its impact on quality of life). Cognitive rehabilitation for memory and executive dysfunction is suggested as one such treatment but considerably more research is required to investigate its efficacy.
- Clinical neuropsychology has an important role to play in the assessment and treatment of cognitive dysfunction. To meet this need the provision and organisation of clinical neuropsychological services needs to be investigated.
- The role of clinical neuropsychology and health psychology in educating both individuals and their families and wider society about epilepsy is also proposed to be important.
- Locus of control is perhaps not one of most important factors to consider in relation to quality of life, although is cannot be discarded completely. It remains something to be mindful of, especially in relation mental health issues and treatment.
- When assessing and working with this client group it is important to be mindful of the influence of anxiety in epilepsy and to consider the potential role clinical and/or health psychologists may play in its assessment and treatment.

4.4 METHODOLOGICAL CONSIDERATIONS

One of the difficulties in drawing conclusions about the results of this study is the reduced power due to the smaller than anticipated numbers. Power calculations indicated that approximately 35 patients would have been required. Despite the chief investigator's best efforts, it was not possible to recruit this number of participants.

The epilepsy nurse was the main source of patients for the study. With hindsight it might have been useful to have involved the consultant neurologists in the patient recruitment process as well. This might have improved the likelihood of reaching power and potentially provided access to a wider range of patients. Regarding the latter point, participants who were seeing the epilepsy nurse tended to have various problems arising from having more intractable temporal lobe epilepsy or from having a recent diagnosis. However, the advantage of using the epilepsy nurse was that she had more frequent contact with patients and therefore was able to comment with more confidence on their suitability for the study in relation to the inclusion/exclusion criteria.

During the selection of neuropsychological assessments to be used in the study it was difficult to find any that were specifically for use or had been validated on epilepsy populations. In addition, there was little consistency in the tests used when investigating cognition in epilepsy. This finding relates to the review by Cochrane et al (1998) which highlights inconsistency in the use of neuropsychological assessments in epilepsy. They recommended epilepsy specific neuropsychological instruments and increased uniformity in selection of tests. Increased consistency in

the assessment tools used would help both researchers and clinical practitioners to reach conclusions and make recommendations with more confidence and certainty.

Following ethical approval, a number of possible alternatives to particular assessments used came to light. Future work in this area might make use of these. A new screening tool for identifying major depression and anxiety in patients with epilepsy has been recently published (Cole, 2006). The Neurological Disorders Depression Inventory for Epilepsy (NODEE) might have been a useful alternative to the Hospital Anxiety and Depression Scale as it has been standardised specifically for use in this population. A new measure has been very recently developed from the Quality of Life in Epilepsy- 31 Item questionnaire used in this study. The QOLIE-31-P includes additional questions regarding how much distress patients feel about problems and worries related to epilepsy. However, the disadvantage of this measure is that it includes additional questions, which means a longer assessment period for each patient. In relation to the QOLIE-31, a recently published paper by Tracy et al (2007) reveals that its scores strongly reflect psychological state, primarily depressed mood, and that factors such as seizure control exert a more limited effect on the QOLIE. This suggests that health related quality of life measures where mood does not play such a dominant role are required.

In relation to the subtests used from the Wechsler Memory Scale - Third Edition (WMS-III), the chief investigator wondered if it had been necessary to separate the immediate and delayed scores. It might have been more straightforward to combine them to have two overall scores for verbal and visual memory. In addition,

information from Bell et al (2004) suggests that separate immediate and delayed WMS-III indices are not necessary in this population. Utilising other memory assessments, such as the California Verbal Test – Second Edition, might also have been interesting as it would have provided more detailed information about different aspects of verbal learning and memory. However, due to the number of assessments being administered it was decided that this would take too long to administer and could potentially cause unnecessary stress to participants.

It would have been interesting to have had a control group in this study comprised of individuals from taken from a non-epileptic clinical population or from group who did not have memory or executive dysfunction. This would have clarified whether the relationship found between memory function and quality of life is more pronounced in epilepsy, or whether memory and quality of life would be equally correlated in other groups.

4.5 FUTURE RESEARCH

During the course of this investigation, a number of areas for possible future research came to light.

There is a lack of research exploring cognitive rehabilitation for both memory and dysexecutive problems in epilepsy. Such work could have significant clinical relevance and implications for the quality of life of patients with temporal lobe epilepsy.

In this study only the perspective of the individuals with epilepsy themselves were sought. Future studies might like to involve and explore the views and thoughts of the individuals' families and/or significant others. Research indicates that significant others may feel grief for the patient, fears for safety, doubts about their own ability to cope and/or resentment due to disruption in their own lives (Usiskin, 2005). In addition, there is research that suggests that cognitive function may impact on the quality of life of carers as well.

Impairment of long-term recall may worsen everyday functioning of patients with epilepsy even if standard short term or delayed recall tests do not show significant abnormalities (Mameniskiene et al, 2006). Individuals with epilepsy frequently complain of memory problems yet perform within normal range on standard neuropsychological memory assessments. It has been suggested that this is due to impairment of very long-term memory consolidation processes which may reflect the disruptive effects of seizures on long-term consolidation of new information (Schulman & Barr, 2002; Blake et al, 2000). This long-term impairment may have missed this in this study as the tests used required retention of new information at a standard 25-30 minute delay. Potentially this long-term impairment, which remains outside of routine cognitive assessment, could be more important to everyday living than immediate and delayed recall (Mameniskiene, 2006).

A number of studies suggest that area of lateralisation is an important area to consider. There is some evidence indicating that individuals with unilateral left epileptic focus have significantly increased risk of memory dysfunction compared

with patients with right temporal lobe epilepsy (McDonald et al, 2005). This also relates to the debate regarding material specific deficits. Future work in this area would possible help to clarify this issue.

REFERENCES

- Alanis-Guevara, I., Pena, E., Corona, T., Lopez-Ayala, T., Lopez-Meza, E. & Lopez-Gomez, M. (2005). Sleep disturbances, socioeconomic status and seizure control as main predictors of quality of life in epilepsy. *Epilepsy and Behaviour*, 7, 481-485.
- Aldenkamp, A.P. & Hendriks, M.P.H. (2000). Managing cognitive and behaviour consequences of epilepsy. In G.A. Baker & A. Jacoby (Eds.), *Quality of Life in Epilepsy*, pp12-31. Amsterdam: Harwood Academic Publishers.
- Aldenkamp, A.P., & Vermeulen, J. (1991). Neuropsychological rehabilitation of memory function in epilepsy. *Neuropsychological Rehabilitation*, 1, 199-214.
- Amir, M., Roziner, I., Knoll, A. & Neufeld, M. (2001). Self efficacy and social support as mediators in the relation between disease severity and quality of life in patients with epilepsy. *Epilepsia*, 40, 216-224.
- Andelman, F., Neufeld, M.Y., Fried, I. (2004). Contribution of Neuropsychology to Epilepsy Surgery. *The Israel Journal of Psychiatry & Related Sciences*, 41, 125-33.
- Anderson, S.W., Damasio, H., Jones, R.D. & Tranel, D. (1991). Wisconsin card sorting test performance as a measure of frontal lobe damage. *Journal of Clinical & Experimental Neuropsychology*, 13, 909-922.
- Au, A., Li, P., Chan, J., Lui, C., Ng, P., Kwok, A. & Leung, P. (2002). Predicting the quality of life in Hong Kong Chinese Adults with epilepsy. *Epilepsy and Behaviour*, 3, 350-357.
- Baker, G.A. (2005). Employment. In J.W. Sander, M.C. Walker & J.E. Smalls (Eds.). In *From Neuron to NICE – A Practical Guide*. International League Against Epilepsy, pp.495-502.
- Baker, G.A. & Jacoby, A. (2002). Health-related quality of life of adults with epilepsy. *Epilepsy & Behavior*, 3, 560-561.
- Baker, G.A. & Moore, P.M. (2002). The neuropsychological and emotional consequences of living with intractable temporal lobe epilepsy: implications for clinical management. *Seizure*, 11, 224-30.
- Baker, G.A. (2001). Why I study...epilepsy. *The Psychologist*, 14, 536-7.
- Baker, G.A., Brooks, J., Buck, D. & Jacoby, A. (2000). The stigma of epilepsy: a European perspective. *Epilepsia*, 41, 98-104.
- Baker, G.A., Jacoby, A., Buck, D., Stalgis, C., Monnet, D. (1997). Quality of Life of people with epilepsy: a European study. *Epilepsia*. 38, 353-362.

- Baker, G.A., Jacoby, A., & Chadwick, D.W. (1996). The associations of psychopathology and epilepsy: A community study. *Epilepsy Research*, 1, 29-29.
- Baker, G.A. Smith, D.F., Dewey M., Jacoby, A. & Chadwick, D.W. (1993). The development of a health-related quality of life model as an outcome measure in epilepsy. *Epilepsy Research*, 16, 65-81.
- Baxendale, S.A., Van Paesschen, W., Thompson, P.J. et al. (1998). Hippocampal cell loss and gliosis: relationship to pre and post-operative memory function. *Neuropsychiatry, Neuropsychology, & Behavioral Neurology*, 11, 12-21.
- Beghi, E. (2007). Epilepsy. *Current Opinion in Neurology*, 20, 169-174.
- Bell, B.D., Hermann, B.P., Seidenberg, M. Significant discrepancies between immediate and delayed WMS-III indices are rare in temporal lobe epilepsy patients. *Clinical Neuropsychologist*, 18, 303-311.
- Benassi, M. Sweeney, B. & Dafour, S. (1988). In J. Maltby, L. Day & A. Macaskill (Eds.), *Personality, Individual Differences and Intelligence*. Harlow: Pearson Prentice Hall.
- Bennett, T.L. (1992). *The neuropsychology of epilepsy*. New York, NY, US: Plenum Press.
- Benton, A.L., Sivan, A.B. & Hamsher, K. et al. (1994). *Contributions to neuropsychological assessment. A clinical manual* (2nd edn). New York: Oxford University Press.
- Benton, A.L. & Hamsher, K.D.S. (1976). *Multilingual aphasia examination*. Iowa City: University of Iowa Press.
- Berg, A.T., Levy, S.R., Novotny, E.J. & Shinnar, S. (1996). Predictors of intractable epilepsy in childhood: A case-control study. *Epilepsia*, 37, 24-30.
- Beyenburg, S.B., Mitchell, A.J., Schmidt, D., Elger, C.E. & Reuber, M. (2005). Anxiety in patients with epilepsy: Systematic review and suggestions for clinical management. *Epilepsy and Behaviour*, 161-171.
- Birbeck, G. L., Sehyun, K., Hays, R.D. & Vickrey, B.G. (2000). Quality of life measures in epilepsy: How well can they detect change over time? *Neurology*, 54, 1822-1827.
- Blake, R.V., Wroe, S.J. Breen, E.K. & McCarthy, R.A. (2000). Accelerated forgetting in patients with epilepsy: Evidence for impairment in memory consolidation. *Brain*, 123, 472-483.
- Bloom, P.A. & Fischler, I. (1980). Completion norms for 329 sentence contexts. *Memory & Cognition*, 8, 631-642.

- Blum, D., Reed, M., & Metz, A. (2003). *Prevalence of major affective disorders and manic/hypomanic symptoms in persons with epilepsy: a community survey*. Paper presented at the meeting of the American Academy of Neurology 54th Annual Meeting, Denver, CO.
- Bondi, M., Monsch, A., Butters, N., Salmon, D. & Paulson, J. (1999). Utility of a modified version of the Wisconsin card sorting test in the detection of dementia of the Alzheimer type. *The Clinical Neuropsychologist*, 7, 161-170.
- Borkowski, J.G., Benton, A.L. & Spreen, O. (1967). Word fluency and brain damage. *Neuropsychologica*, 5, 135-140.
- Bortz, J.J. (2003). Neuropsychiatric and Memory Issues in Epilepsy. *Mayo Clinic Proceedings: Symposium on Seizures*, 78, 781-787.
- Bougakov, D. (2005). Executive dysfunction in post-amygdala-hippocampectomised epilepsy patients. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 65, 6643.
- Boylan, L.S., Flint, L.A., Labovitz, D.L., Jackson, S.C., Starner, K. & Devinsky, O. (2004). Depression but not seizure frequency predicts quality of life in treatment-resistant epilepsy. *Neurology*, 62, 258-261.
- Bryson, G. Whelan, H.A., Bell. (2001). Memory and executive function impairments in deficit syndrome schizophrenia. *Psychiatry Research*, 102, 29-37.
- Buck, D. Jacoby, A., Baker, G.A., Ley, H. & Steen, N. (1999). Cross sectional differences in health-related quality of life of people with epilepsy: findings from a European study. *Quality of Life Research*, 8, 675-685.
- Burgess, P.W. & Shallice, T. (1997). *The Hayling and Brixton Test: Test Manual*. Thurston, Suffolk, England: Thames Valley Test Company.
- Butler, M., Retzlaff, P. & Vanderploeg, R.D. (1991). Neuropsychological test usage. *Professional Psychology: Research and Practice*, 22, 510-512.
- Chadwick, D.W. (2005). Classification of seizures. In J.W. Sander, M.C. Walker & J.E. Smalls (Eds.). In *From Neuron to NICE – A Practical Guide*. International League Against Epilepsy, pp.495-502.
- Chan, C.C.H. & Lee, T.M.C. (2000). Are Trail Making and Colour Trails Tests of Equivalent Constructs? *Journal of Clinical and Experimental Neuropsychology*, 22, 529-534.
- Clark, C., Prior, M., & Kinsella, G. J. (2000). Do executive function deficits differentiate between adolescents with ADHD and oppositional defiant/conduct disorder? A neuropsychological study using the Six Elements Test and Hayling Sentence Completion Test. *Journal of Abnormal Child Psychology*, 28, 403-414.

- Cochrane, H.C., Marson, A.G. Baker, G.A. & Chadwick, D.W. (1998). Neuropsychological Outcomes in randomised control trials of antiepileptic drugs: a systematic review of methodology and reporting standards. *Epilepsia*, 39, 1088-97.
- Commission on Classification: International League Against Epilepsy (1981). Proposed provisions of clinical and electrocephalographical classification of epileptic seizures. *Epilepsia*, 22, 489-501.
- Cramer, J.A. & VanHammee, G. (2003) Maintenance of improvement of health related quality of life during long term treatment with levetiracetam. *Epilepsy Behaviour*, 4, 118-123.
- Cramer, J.A. (1999). Quality of Life assessment in clinical practice. *Neurology*, 53, 49-52.
- Crawford, J. & Henry, J. (2005). Assessment of executive dysfunction. In Halligan, P.W. & Wade, D.T. *Effectiveness of Rehabilitation for Cognitive Deficits*, pp 233-245. Oxford University Press.
- Cull, C. & Goldstein, L.H. (1997). An Introduction to Epilepsy. In C. Cull & L.H. Goldstein, (Eds.), *The Clinical Psychologist's Handbook of Epilepsy: Assessment and Management*, pp.1-17. Routledge: London.
- Currie, S., Heathfield, K.W., Henson, R.A., & Scott, D.F. (1971). Clinical Course and prognosis of temporal lobe epilepsy: a survey of 666 patients. *Brain*, 94, 173-90.
- Delaney, R.C., Rosen, A.J., Mattson, R.H. & Novelly, R.A. (1980). Memory function in focal epilepsy; a comparison of non-surgical unilateral temporal lobe and frontal lobe samples. *Cortex*, 16, 103-117.
- D'Elia, F.D & Satz, P. (1996). *Colour Trails 1 and 2*. Odessa, FL: Psychological Assessment Resources, Inc.
- DeVillis, R.F., DeVillis, B.M. An evolving psychosocial model of epilepsy. In S. Whitman. & B.F. Hermann (Eds.), *Psychopathology in epilepsy: social dimensions*, pp.122-142. New York: Oxford University Press.
- Devinsky, O., Vickrey, B. & Cramer, J. (1995). Development of quality of life in epilepsy inventory. *Epilepsia*, 37, 148-61.
- Dewhurst, K. & Beard, A.W. (2003). Classics in Epilepsy and Behaviour: 1970. Sudden Religious Conversions in temporal lobe epilepsy. *Epilepsy & Behaviour*, 4, 78-87.
- Dilorio, C., Faherty, B & Manteuffel, B. (1992). Self-efficacy and social support in self-management of epilepsy. *Western Journal of Nursing Research*, 14, 292-303.

- Djibuti, M. & Shakarishvili, R. (2003). Influence of clinical, demographic and socioeconomic variables on quality of life in patients with epilepsy: findings from Georgian study. *Journal of Neurology Neurosurgery & Psychiatry*, 74, 570-573.
- Dodrill (1988). Effects of antiepileptic drugs on abilities. *Journal of Clinical Psychiatry*, 49, 31-4.
- Dodrill, C.B. (1986). Correlates of generalized tonic-clonic seizures with intellectual, neuropsychological, emotional, and social function in patients with epilepsy, *Epilepsia*, 27, 399-411.
- Dori, G.A. & Chelune, G. J. (2004). Education-Stratified Base-Rate Information on Discrepancy Scores Within and Between the Wechsler Adult Intelligence Scale - Third Edition and the Wechsler Memory Scale - Third Edition. *Psychological Assessment*, 16, 146-154. American Psychological Association.
- Dow, C., Seidenberg, M., Hermann, B. (2004). Relationship between information processing speed in temporal lobe epilepsy and white matter volume. *Epilepsy & Behaviour*, 5, 919-925.
- Duff, K., Schoenberg, M.R., Scott, J.G. & Adams, R.L. (2005). The relationship between executive functioning and verbal and visual learning and memory. *Archives of Clinical Neuropsychology*, 20, 111-122.
- Duglos, D.J. (2001). The early identification of candidates for epilepsy surgery. *Archives of Neurology*, 58, 1543-1546.
- Elger, C.E., Helmstaedter, C., and Kurthen, M. (2004). Chronic epilepsy and cognition, *Lancet Neurol*, 3, 663-672.
- Elixhauser, A., Kline Leidy, N., Meador, K., Means., & Willain, M.K. (1999). The relationship between memory performance, perceived cognitive function, and mood in patients with epilepsy. *Epilepsy Research*, 37,13-24.
- Ellis, A., Hiram, J., Cardno, A. & Kay, J. (1991). Processing of words and faces by patients with left and right temporal lobe epilepsy. *Behavioural Neurology*, 4, 121-138.
- Engel, J., Wieser, H.G. & Spencer, D. (1997). Overview: Surgical Therapy. In Engel, J. & Pedley, T (Eds.) *Epilepsy*, pp 1673-1676. Philadelphia: Lippincott-Raven.
- Engel, J., Jr. (Ed). (1993). *Surgical treatment of the epilepsies* (2nd Edition). New York: Ravens Press.
- Engelberts, N.H.J., Klein, M., Van der Ploeg, H.M., Heimanse, J.J., Jolles, J., D.G.A. Kasteleijn-Nolst Trenite. (2002). Cognition and health related quality of life in chronic well-controlled patients with partial epilepsy on carbamazepines monotherapy. *Epilepsy & Behaviour*, 316-321.

- Exner, C., Boucsein, K., Lange, C., Winter, H., Weniger, G., Steinhoff, B.J et al. (2002). Neuropsychological performance in frontal lobe epilepsy. *Seizure*, 11, 20-32.
- Evans, J.J. (2005) Can executive impairments be effectively treated? In Halligan, P. and Wade, D. (Eds.) *The Effectiveness of Rehabilitation for Cognitive Deficits*. Oxford: Oxford University Press.
- Fallowfield, L. (1990). *The Quality of Life. The Missing Measurement in Health Care*. London: Souvenir Press.
- Fedderson, B., Herzer, R., Hartman, U., Gaab, M.R. & Runge, U. (2005). On the Psychopathology of uniltateral temporal lobe epilepsy. *Epilepsy & Behaviour*, 6, 43-49.
- Fenwick, P (1994). *Untitled*. Paper presented at the 4th International Science Symposium on Science and Consciousness.
- Fisher, R.S. Vickrey, B.G. Gibson, P. et al. (2000). The impact of epilepsy from the patient's perspective I and II. *Epilepsy Research*, 41, 39-61.
- Fowler, A.J. & Binnie, C.D. (2000). Uses and abuses of the EEG in epilepsy. *Epilepsia*, 41.
- Frucht, M.M., Quigg, M., Schwaner, C. & Fountain, N.B. (2000). Distribution of seizure precipitants among epilepsy syndromes. *Epilepsia*, 41, 1534-1539.
- Fujii, D.E., Wylie, A.M, & Nathan, J.H. Neurocognition and long-term prediction of quality of life in outpatients with severe and persistent mental illness. *Schizophrenia Research*, 69 (1), 67-73.
- Gehlert, S. (1994). Perceptions of Control in adults with epilepsy. *Epilepsia*, 35, 81-88.
- Gestaut, H. (1973). *Dictionary of Epilepsy*. World Health Organisation: Geneva.
- Giovagnoli, A.R. & Avanzini, G. (2000). Quality of Life and memory performance in patients with temporal lobe epilepsy. *Acta Neurologica Scandinavica*, 101(5), 295-300.
- Giovagnoli, A.R., Mascheroni, S. & Avanzini, G. (1997). Self-reporting of everyday memory in patients with epilepsy: relation to neuropsychological, clinical, pathological and treatment factors. *Epilepsy Research*, 28, 119-28.
- Goldstein, M.A. & Harden, C.L. (2000). Epilepsy and anxiety. *Epilepsy & Behaviour*, 1, 228-34.
- Grabowska-Grzyb, A., Jedrzejczak, J., Naganska, E. & Fiszer, U. (2006). Risk factors for depression in patients with epilepsy. *Epilepsy & Behaviour*, 8, 411-417.

- Gupta, A. & Naorem, T. (2003). Cognitive retraining in epilepsy. *Brain Injury*, 17, 161-174.
- Halgren, E., Stapleton, J., Domalski, T., Swartz, B.E., Delgado-Escueta, A.V. & Walsh, G.O. (1991). Memory dysfunction in epilepsy: patient as a derangement of normal physiology. In D. Smith, D. Treiman & M. Trimble (Eds.), *Advances in Neurology*, 55: *Neurobehavioural Problems in Epilepsy*. New York: Raven Press.
- Harden, C. (2002). The co-morbidity of depression and epilepsy: Epidemiology, aetiology, and treatment. *Neurology*, 59, 48-55.
- Hawley, B. (2006). Effects of spaced retrieval on memory and quality of life in older adults with probable Alzheimer's disease. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 66, 3973.
- Heaton, R.K. (1981). Wisconsin Card Sorting Test. Odessa, Florida: Psychological Assessment.
- Helmstaedter, C. & Gates, J. (2006). Syndromes III: "Nonidiopathic" (Cryptogenic and Symptomatic) Focal Epilepsies with Special Consideration of Temporal Lobe Epilepsy (TLE). *Epilepsia*, 47, 90.
- Helmstaedter, C. (2001). Behavioural Aspects of frontal lobe epilepsy. *Epilepsy & Behaviour*, 2, 384-395.
- Helmstaedter, C., Grunwald, T., Lehnertz, K., Gleissner, U. & Elger, C.E. (1997). Differential involvement of left temporolateral and temporomesial structures in verbal declarative learning and memory: Evidence from temporal lobe epilepsy. *Brain and Cognition*, 35, 110-131..
- Hendriks, M.P.H. Aldencamp, A.P. Van der Vlugt, H, Aplherts, W.C.J. & Vermeulen, J. (2002). Memory complaints in medically refractory epilepsy: relationship to epilepsy-related factors. *Epilepsy Behaviour*, 3, 165-72.
- Hendriks, M.P.H (2001). Neuropsychological compensatory strategies. In R.T. Pfaddlin, R. Fraser, S.U. Thorbecke, U. Spechte & P. Wolf (Eds.), *Comprehensive care for people with epilepsy*, pp.87-94. John Libbey.
- Hendriks, M., Aldencamp, A.P. & Van der Vlugt, H. (1999). Neuropsychological assessment of memory functions in epilepsy. In D. Schmidt & S.C. Schacter (Eds.), *Epilepsy: problem solving in clinical practice*, pp.191-202. London: Martin Dunitz, 191-202.
- Hermann, B. & Seidenberg, M. (2007). Epilepsy & Cognition. *Current Review in Clinical Science: Epilepsy Current Review*, 7, 1-6.

- Hermann, B., Seidenberg, M. & Bell, B. (2003.) Extratemporal quantitative MR volumetrics and neuropsychological status in temporal lobe epilepsy, *Journal of International Neuropsychology*, 9, 353–362.
- Hermann, B., Seidenberg, M., Bell, B., Rutecki, P., Sheth, R., Ruggles, K., Wendt, G., O'Leary, D. & Magnotta, V. (2002). The neurodevelopmental impact of childhood-onset temporal lobe epilepsy on brain structure and function. *Epilepsia*, 43, 1062-1071.
- Hermann, B.P., Seidenberg, M. & Woodard, A.R. (1996). Memory and epilepsy: current perspectives. *Clinical Nurse Practitioner in Epilepsy*, 3, 4-8.
- Hermann, B. & Seidenberg, M. (1995). Executive system dysfunction in temporal lobe epilepsy: Effects of nociferous cortex versus hippocampal pathology. *Journal of Clinical and Experimental Neuropsychology*, 17, 809-819.
- Hermann, B., Wyler, A.R. & Richey, E.T. (1988). Wisconsin card sorting test performance in patients with complex partial seizures of temporal lobe origin. *Journal of Clinical & Experimental Neuropsychology*, 10, 467-476.
- Herodes, M., Oun, A., Haldre, S. & Kaasik, A.E. (2001). Epilepsy in Estonia: a quality-of-life study. *Epilepsia*, 42, 1061-73.
- Hesdorffer, D.C., Hauser, W.A., Olafsson, E., Ludvigsson, P. & Kjartansson, O. (2006). Psychopathology and Epilepsy: Is it the chicken or the egg? *Annals of Neurology*, 59, 35-41.
- Hesdorffer, D., Hauser, W., Annegers, J., & Cascino, G. (2000). Major depression is a risk factor for seizures in older adults. *Annals of Neurology*, 47, 246-249.
- Hershey, T., Craft, S., Glauser, T. A., Hale, S. (1998). Short-Term and Long-Term Memory in Early Temporal Lobe Dysfunction. *Neuropsychology*, 12, 52-64.
- Hogg, M. & Vaughan, G (1995). *Introduction to social psychology*. Sydney: Prentice Hall.
- Horner, M.D., Flashman, L.A., Freides, D. et al (1996). Temporal lobe epilepsy and performance on the Wisconsin card sorting test. *Journal of Clinical & Experimental Neuropsychology*, 18, 310-313.
- Hornquist, J.O. (1982). The concept of quality of life. *Scandinavian Journal of Social Medicine*, 10, 57-61.
- Hughes J.R. (2005). "Did all those famous people really have epilepsy?". *Epilepsy & Behaviour*, 6, 115-39.

- Isaacs, K.L., Philbeck, J.W., Barr, W.B., Devinsky, O. & Alper, K. (2004). Obsessive Compulsive Disorder in patients with temporal lobe epilepsy. *Epilepsy & Behaviour*, 5, 569-574.
- Jacoby, A., Baker, G.A., Steen, A., Potts, P. & Chadwick, D.W. (1996). The clinical course of epilepsy and its psychosocial correlates: Findings from a UK community study. *Epilepsia*, 37, 148-161.
- Jahnukainen, H. (1995). Psychosocial consequences of intractable epilepsy in adult. In S.I. Johannessen, L. Gram, M. Sillanpaa & T. Tomson. (Eds.), *Intractable Epilepsy*, pp.165-169. Bristol, PA: Wrightson Biomedical Publishing Ltd.
- Jilek-Aall, L. (1999). Morbus sacer in Africa: some religious aspects of epilepsy in traditional cultures. *Epilepsia*, 40, 382-6.
- Johnson, E.K., Jones, J.E., Seidenberg, M. & Hermann, B.P. (2004). The relative impact of anxiety, depression, and clinical seizure features on health-related quality of life in epilepsy. *Epilepsia*, 45, 838-43.
- Jokeit, H., Kramer, G. and Ebner, A. (2005). Do antiepileptic drugs accelerate forgetting? *Epilepsy & Behaviour*, 6, 430-432.
- Jokeit, H., Seitz, R.J., Markowitsch, H.J., Neuman, N., Witte, O.W. & Ebner, A. (1997). Prefrontal asymmetric interictal glucose hypometabolism and cognitive impairment in patients with temporal lobe epilepsy. *Brain*, 120, 2283-2294.
- Jones-Gottman (1987). Commentary: psychological evaluation—testing hippocampal function. In J Engel (Ed.), *Surgical Treatment of the Epilepsies*, pp.181-195. New York, Raven Press.
- Kanner, A.M. (2003). Depression in epilepsy: prevalence, clinical semiology, pathogenic mechanisms, and treatment. *Biological Psychiatry*, 54, 388-398.
- Kendrick, A.M. (1997). Repertory grid technique in the assessment of quality of life in patients with epilepsy. Unpublished PhD thesis, University of London.
- King M.A., Newton M.R., Jackson G.D., Fitt, G.J., Mitchell L.A., Silvapulle, M.J. et al. (1998). Epileptology of the first seizure presentation: a clinical, electroencephalographic, and magnetic resonance imaging study of 300 consecutive patients. *Lancet*, 352, 1007-11.
- Kwan, P. & Brodie, M.J. (2001). Neuropsychological Effects of epilepsy and antiepileptic drugs. *Lancet*, 357, 216-22.
- Lammers, M.W., Hekster, Y.A., Keyser, A.A., Meinardi, H.H. Reiner, W.O. & Van Lier, H. (1995). Monotherapy or polytherapy for epilepsy revisited: a quantitative assessment. *Epilepsia*, 36, 440-446.

- Lau, V.W., Lee, T., Ng, P., & Wong, V. (2001). Psychosocial Adjustment of People with Epilepsy in Hong Kong. *Epilepsia*, 42, 1169-1175.
- Lennox, W.G. (1942). Brain injury, drugs and environment as causes of mental decay in epilepsy. *American Journal of Psychiatry*, 99, 174-180.
- Leritz, E.C., Grande, L.J, Bauer, R.M (2006). Temporal Lobe epilepsy as a model to understand human memory: The distinction between explicit and implicit memory. *Epilepsy & Behaviour*, 9, 1-13.
- Lesser, R.P., Luderss, H., Wyllie, E., et al. (1986). Mental deterioration in epilepsy. *Epilepsia*, 27, 105-123.
- Levenson, H. (1973). Multidimensional locus of control in psychiatric patients. *Journal of Consulting and Clinical Psychology*, 41, 397-404.
- Levin, R., Banks, S. & Bero, B. (1988). Psychosocial dimensions of epilepsy: a review of the literature. *Epilepsia*, 29, 805-16.
- Lewis, A. (1934). Melancholia: a historical review. *Journal of Mental Science*, 80, 1-42.
- Lezak, M.D., Howieson, D.B. & Loring, D.W (2004). *Neuropsychological Assessment* (4th edn). Oxford University Press.
- Lishman, W.A. (1997). *Organic Psychiatry* (3rd edn). Oxford: Blackwell Scientific Publications.
- Logiudice, D., Waltrowicz, W., Brown, K., Burrows, C., Ames, D. & Flicker, L. (1999). Do memory clinics improve the quality of life of carers? A randomised pilot trial. *International Journal of Geriatric Psychiatry*, 14, 626-632.
- Loring, D.W. & Meador, K.J. (2001). Cognitive and behavioural effects of epilepsy treatment. *Epilepsia*, 42, 24-32.
- MacLeod, J.S. & Austin, J.K. (2003). Stigma in the lives of adolescents with epilepsy: a review of the literature. *Epilepsy & Behaviour*, 4, 112-7.
- Maj, M., D'Elia, L.F., Satz, P., Jannsen, R., Zaudig, M., Uchiyama, C. et al. (1993). Evaluation of two new neuropsychological tests designed to minimise cultural bias in the assessment of HIV-1 seropositive persons: A WHO study. *Archives of Neuropsychology*, 8, 123-135.
- Mameniskiene, R., Jatuzis, D., Kaubrys, L. & Budrys, V. (2006). The decay of memory between delayed and long term recall in patients with temporal lobe epilepsy. *Epilepsy & Behaviour*, 8, 278-288.

- Marczewski, P., Van der Linden, M., & Laroi, F. (2001). Further investigation of the supervisory attentional system in schizophrenia: Planning, inhibition, and rule abstraction. *Cognitive Neuropsychiatry*, 6, 175-192.
- Marsh, L. & Rao, V. (2002). Psychiatric complications in patients with epilepsy: a review. *Epilepsy Research*, 49, 11-33.
- Marson, A.G., Al-Kharusi, A.M., Alwaidh, M., Appleton, R., Baker, G.A., Chadwick et al. (2007). SANAD Study group. The SANAD study of effectiveness of carbamazepine, gabapentin, lamotrigine, oxcarbazepine, or topiramate for treatment of partial epilepsy: an unblinded randomised controlled trial. Randomized Controlled Trial. *Lancet*, 369, 1000-1015.
- Marson, A.G., Al-Kharusi, A.M., Alwaidh, M., Appleton, R., Baker, G.A., Chadwick D.W. et al. (2007). The SANAD study of effectiveness of valproate, lamotrigine, or topiramate for generalised and unclassifiable epilepsy: an unblinded randomised controlled trial. Multicenter Study. Randomized Controlled Trial. *Lancet*, 369, 1016-26.
- Martin, R.C., Bortz, J.J. & Synder, P.J. (2006). Epilepsy and Nonepileptic Seizure Disorders. In P.J. Synder, P.D. Nussbaum & D.L. Robins (Eds.), *Clinical Neuropsychology: a Pocket Handbook for Assessment (Second Edition)*, pp.318-345. American Psychological Association: Washington DC.
- Matthews, W. S. & Barabas, G. (1981). Suicide and epilepsy: a review of the literature. *Psychosomatics*, 22, 515-524.
- Matthews, W.S., Barabas, G. & Ferrari, M. (1982). Emotional concomitants of childhood epilepsy. *Epilepsia*, 23, 671-681.
- McDermid, V., Stephanie, A. & Heinrichs, R.W. (2002). Schizophrenia and memory impairment: Evidence for a neurocognitive subtype. *Psychiatry Research*, 113, 93-105.
- McDonald, C.R., Delis, D.C., Norman, M.A., Spencer, R.W., Tecoma, E.S. & Vicente, J.I. (2005). Response inhibition and set shifting in patients with frontal lobe epilepsy or temporal lobe epilepsy. *Epilepsy & Behaviour*, 7, 438-446.
- McLachlan, R.S, Rose, K.J., Derry, P.A., Bonnar, C., Blume, W.T., & Girvin, J.P. (1997). Health-related quality of life and seizure control in temporal lobe epilepsy. *Annals of Neurology*, 41, 482-9.
- McLeod, J.S. & Austin, J.K. (2003). Stigma in the lives of adolescents with epilepsy: a review of the literature. *Epilepsy Behaviour*, 4, 112-117.

- Meador, K.J. (2001). Cognitive effects of epilepsy and antiepileptic medications. In E. Wyllie (Ed.), *The treatment of epilepsy* (3rd edn), pp.1215-1227. Baltimore: Williams & Wilkins.
- Meador, K.J., Gilliam, F.G., Kanner, A.M. & Pellock, J.M. (2001). Cognitive and behavioural effects of antiepileptic drugs. *Epilepsy Behaviour*, 2, 1-17.
- Meador, K., Loring, D.W., Allen, M.E., Zamrini, Y., Moore, E.E. & Abney, O.L. (1991). Comparative cognitive effects of carbamazepine and phenytoin in healthy adults. *Neurology*, 41, 1537-1540.
- Mensah, S.A., Beavis, J.M., Thapar, A.K. & Kerr, M. (2006). The presence and clinical implications of depression in a community population of adults with epilepsy. *Epilepsy & Behaviour*, 8, 1213-1219.
- Miller, L.A. (1992). Impulsivity, risk-taking and the ability to synthesise fragmented information after frontal lobectomy, *Neuropsychologica*, 30, 69-72.
- Mitrushina, M.N., Boone, K.B. & D'Elia, L.F. (1999). *Handbook of normative data for neuropsychological assessment*. New York: Oxford University Press.
- Moore, P.M. & Baker, G.A. (2002). The neuropsychological and emotional consequences of living with intractable temporal lobe epilepsy: implications for clinical management. *Seizure*, 11, 224-230.
- Moses, A. (2004). Review of Comprehensive Trail Making Test (CTMT). *Archives of Clinical Neuropsychology*, 19, 703-708.
- The National Society for Epilepsy. (2006). *Information on Epilepsy: Did you know?* Retrieved 10 January 2007 from www.epilepsynse.org.uk/pages/info/leaflets/epfacts.cfm.
- National Institute for Health & Clinical Excellence (2004). *The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care*. Clinical Guideline 20.
- Norman, P. & Bennett, P. (1995). Health Locus of Control. In M. Conner & P. Norman (Eds.), *Predicting Health Behaviour*, pp.62-94. Buckingham: Open University Press.
- Nunally, J. (1978). *Psychometric Theory* (2nd edn). New York: McGraw-Hill.
- Odhuba, R. A. & Broek, M.D. (2005) Ecological validity of measures of executive functioning. *British Journal of Clinical Psychology*, 44, 269-278.
- O'Donoghue, M.F., Goodridge, D.M., Redhead, K., et al. (1999). Assessing the psychosocial consequences of epilepsy: a community-based study. *British Journal of General Practitioners*, 49, 211-4.

- Penades, R., Catalan, R., Salamero, M., Boget, T., Puig, O., Guarch, J. & Gasto, C. (2006). Cognitive Remediation Therapy for outpatients with chronic schizophrenia: A controlled and randomized study. *Schizophrenia Research*, 87, 323-331.
- Perrine, K., Gershengorm, J. & Brown, E.R. (1991). Interictal neuropsychological function in epilepsy. In O. Devinsky & W.S. Theodore, (Eds.), *Epilepsy & Behaviour*. New York: Wiley-Liss.
- Perrine, K. (1993). A new quality-of-life inventory for epilepsy patients: interim results. *Epilepsia*, 34, 8-33.
- Perrine, K., Hermann, B., Meador, K.J., Vickrey, B.G. Cramer, J.A. & Hays, R.D. et al. (1995). The Relationship of Neuropsychological Functioning to Quality of Life in Epilepsy. *Archives of Neurology*, 52, 997-1003.
- Perini, G.I., Tosin, C., Carraro, C., Bernasconi, G., Canevini, M.P. Canger, M.P., Pelligrini, A. & Testa, G. (1996). Interictal mood and personality disorders in temporal lobe epilepsy and juvenile myoclonic epilepsy. *Journal of Neurology, Neurosurgery and Psychiatry*, 61, 601-601.
- Ponds, R. & Hendriks, M. (2006). Cognitive rehabilitation of memory problems in patients with epilepsy. *Seizure*, 15, 267-273
- Preau, M., Vincent, E., Spire, B., Reliquet, V., Fournier, I., Michelet, C., Leport, C. & Morin, M. Health-related quality of life and health locus of control beliefs among HIV-infected treated patients. *Journal of Psychosomatic Research*, 59, 407-413.
- Privitera, M. & Ficker, D.M. (2004). Assessment of adverse events and quality of life in epilepsy: design of a new community trial. *Epilepsy & Behaviour*, 5, 841-846.
- Quiske, A., Helmstaedter, C., Lux, S. & Elger, C.E. (2000). Depression in patients with temporal lobe epilepsy is related to mesial temporal sclerosis. *Epilepsy Research*, 39, 121-125.
- Reitan, R.M. & Wolfson, D. (1993). *The Halstein-Reitan Neuropsychological Test Battery: Theory & Clinical Applications* (2nd edn). Tucson, AZ: Neuropsychology Press.
- Ringe, W.K. (2000). Relationships between executive functioning and quality of life in epilepsy surgery candidates. *Disseration Abstracts International: Section B: The Sciences & Engineering*, 61, 1650.
- Rotter, J.B. (1954). *Social Learning & Clinical Psychology*. New Jersey: Prentice-Hall.
- Sanchez-Carpintero, R. & Neville, B.G.R (2003). Attentional ability in children with epilepsy. *Epilepsia*, 44, 1340-1349.

- Sander, J.W. (2003). The epidemiology of epilepsy revisited. *Current Opinion in Neurology*, 16, 165-170.
- Sander, J.W. (2005). Ultimate success in epilepsy- The patient's perspective. *European Journal of Neurology*, 12, 3-11.
- Sander, J.W. & Shorvon, S.D. (1996). Epidemiology of the epilepsies. *Journal of Neurology, Neurosurgery & Psychiatry*, 61, 433-443.
- Sander, J. W. (1993). Some aspects of the prognosis in the epilepsies: a review. *Epilepsia*, 34, 1007-1016.
- Sander, J.W., Hart, Y.M., Johnson, A.L. & Shorvon, S.D. (1990). National General Practice Study of Epilepsy: newly diagnosed epileptic seizures in a general population. *Lancet*, 336, 1267-1271.
- Schmid-Schonbein, C. (1998). Improvement of seizure control by psychological method in patients with intractable epilepsies. *Seizure*, 7, 261-270.
- Schwartz, J. & Cummings, J.L. (1988). Psychopathology in epilepsy: an outpatient consultation-liaison experience. *Psychosomatics*, 29, 95-300.
- Scottish Intercollegiate Guidelines Network. (2003). *Diagnosis and Management of Epilepsy in Adults. A National Clinical Guideline*, 70, 1-54. NHS Scotland.
- Seidenberg, M., Hermann, B., Noe, A. & Wyler, A.R. (1995). Depression in temporal lobe epilepsy: interaction between laterality of lesion and Wisconsin Card Sort Performance. *Neuropsychiatry, Neuropsychology & Behavioural Neurology*, 8, 81-87.
- Seligman, M.E.P. (1975). *Helplessness: depression, development and death*. New York: W H Freeman.
- Shafer, P.O. (2002). *Symposium on Seizure Management: Vol 111 Improving the quality of life in epilepsy: Non medical issues too often overlooked* (pp.1-9). Postgraduate Medicine Online.
- Sherman, E.M.S., Slick, D.J. & Eyrl, K.L. (2006). Executive Dysfunction is a Significant Predictor of Poor Quality of Life in Children with Epilepsy. *Epilepsia*, 47, 1936-1942.
- Shulman, M.B. & Barr, W. (2002). Treatment of memory disorders in epilepsy. *Epilepsy & Behaviour*, 3, 30-34.
- Silverstein, S.M., Wilkniss, S.M. The Future of Cognitive Rehabilitation of Schizophrenia. *Schizophrenia Bulletin*, 30, 679-692.

- Sillanpaa, M., Haataja, L. & Shinnar, S. (2004). Perceived impact of childhood onset on quality of life as an adult. *Epilepsia*, 45, 971-977.
- Smith, D.B. Craft, B.R., Collins, J., et al. (1996). Behavioural characteristics of epilepsy patients compared with normal controls. *Epilepsia*, 27, 760-768.
- Soederberg Miller, L.M. & Lachman, M.E. (2000). Cognitive performance and the role of control beliefs in midlife. *Neuropsychology, and Cognition*, 7, 69-85
- Spencer, D.D. & Spencer, S.S. (1985). Surgery for epilepsy. *Neurologic Clinics*, 3, 313-330.
- Spitzer, W.O. (1987). State of Science 1986: quality of life and functional status as target variables for research. *Journal of Chronic Disease*, 40, 465-71.
- Spreen, O. & Strauss, E. (1998). *A compendium of neuropsychological tests* (2nd Edition). New York: Oxford University Press.
- Squire, L.R. (1992). Memory and the Hippocampus: a synthesis from findings with rats, monkeys and humans. *Psychological Review*, 99, 195-231.
- Stavem, K., Lossius, M.I., Kvien, T.K. & Guldvog, B. (2000). The health-related quality of life of patients with epilepsy compared with angina pectoris, rheumatoid arthritis, asthma and chronic obstructive pulmonary disease. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 9, 865-871.
- Strauss, E., Hunter, M. & Wada, J. (1993). Wisconsin Card Sorting performance: Effects of age of onset of damage and laterality of dysfunction. *Journal of Clinical and Experimental Neuropsychology*, 15, 896-902.
- Strauss, E., Hunter, M. & Wada, J. (1995). Risk factors for cognitive impairment in epilepsy. *Neuropsychology*, 9, 457-463.
- Sullivan, K. (1995). Alternate forms of prose passages for the assessment of auditory-verbal memory. *Archives of Clinical Neuropsychology*, 20, 745-753.
- Sweet, J.J., Nelson, N.W. & Moberg, P.J. (2006). The TCN/AACN 2005 "salary survey": Professional practices, beliefs, and incomes of U.S. neuropsychologists. *The Clinical Neuropsychologist*, 20, 325-364.
- Swinkels, W.A.M., Kuyk, J., De Graaf, E.H., Van Dyck, R. & Spinhoven, P.H. (2001). Prevalence of psychopathology in Dutch epilepsy patients: a comparative study. *Epilepsy & Behaviour*, 2, 441-447.
- Swinkels, W.A., Kuyk, J., DeGraaf, E.H., van Dyck, R. & Spinhoven, P.H. (2003). Prevalence of psychopathology in Dutch epilepsy inpatients: A comparative study. *Epilepsy & Behaviour*, 2, 441-7.

- Swinkels, W.A., Van Emde Boas, W., Kuyk, J. & Spinhoven, P., (2006). Interictal Depression, Anxiety, Personality Trait, and Psychological Dissociation in Patients with Temporal Lobe Epilepsy (TLE) and Extra TLE. *Epilepsia*, 47, 2092-2103.
- Taher, T.R., Salzburg, M., Morris, M.J., Rees, S. & O'Brien, T.J. (2005). Chronic Low-Dose Corticosterone Supplementation Enhances Acquired Epileptogenesis in the Rat Amygdala Kindling Model of TLE. *Neuropsychopharmacology*, 30, 1610-1616.
- Thompson, P.J. & O'Toole, A. (2005). Psychosocial outcome. In Sander, Walker, M.C. & Smalls, J.E. (Eds.). In *From Neuron to NICE – A Practical Guide*. International League Against Epilepsy, 395-400.
- Thompson, P.J. (1997). Epilepsy and Memory. In C. Cull & L.H. Goldstein (Eds.), *The Clinical Psychologist's Handbook of Epilepsy*, pp. 35-53. Routledge: London.
- Thompson, P.J. & Corcoran, R. (1992). Everyday memory failures in people with epilepsy. *Epilepsia*, 33, 6.
- Tracy, J.L., Denchant, V., Sperling, M.R., Cho, R. & Glosser, D. (2007). *Neurology*, 68, 1101-1107.
- Tremont, G., Halpert, S., Javorsky, D.J. & Stern, R.A. (2000). Differential impact of executive dysfunction on verbal list learning and story recall. *The Clinical Neuropsychologist*, 14, 295-302.
- Trimble, M.R., Ring, H.A., & Schmitz, B. (1996). Neuropsychiatric aspects of epilepsy. In B.S. Fogel (Ed.). *Neuropsychiatry*. Baltimore, MD: Williams & Wilkins.
- Trimble, M.R. (1994). Cognition and QOL. In M.R. Trimble & W.E. Dodson (Eds.), *Epilepsy & Quality of Life*. New York, Raven Press.
- Usiskin, S. (2005). The patient's viewpoint. In Sander, Walker, M.C. & Smalls, J.E. (Eds.). In *From Neuron to NICE – A Practical Guide*. International League Against Epilepsy, pp.485-488.
- Van Rijckevorsel, K. (2006). Cognitive Problems related to epilepsy syndromes especially malignant epilepsies. *Seizure*, 15, 227-234.
- Vazquez, B & Devinsky, O. (2003). Epilepsy and anxiety. *Epilepsy & Behaviour*, 4, 20-25.
- Verhaeghen, P., Geraerts, M.A. & Marcoen, A. (2000). Memory Complaints, Coping and Well-Being in Old Age: A Systemic Approach. *The Gerontologist*, 40, 540-548.
- Vermeulen, J. & Aldenkamp, A.P. (1995). Cognitive side effects of antiepileptic drug treatment: a review of 25 years of research. *Epilepsy Research*, 22, 65-95.

- Vickrey, B.G., Hays, R.D., Graber, J., Rausch, R., Engel, J & Brook, R.H. (1993). A health-related quality of life instrument for patients evaluated for epilepsy surgery, *Medicine Care*, 30, 299-319.
- Wallston, K.A. (2001). Conceptualisation and operationalisation of perceived control. In A. Baum, T. Revenson & J.E. Singer (Eds.) *The Handbook of Health Psychology*, pp.49-58. Mahwah, NJ: Erlbaum.
- Wallston, K.A., Stein, M.J. & Smith, K.A. (1994). Form C of the MHLC Scales: A condition-specific measure of locus of control. *Journal of Personality Assessment*, 63, 534-553.
- Wallston, K.A. (1992). Hocus-Pocus, the focus isn't strictly on locus: Rotter's social learning theory modified for health. *Cognitive Theory & Research*, 16, 183-199.
- Wallston, K.A., Wallston, B.S. & DeVellis, R. (1978). Development of the Multidimensional Health Locus of Control (MHLC) Scales. *Health Education Monographs*, 6, 160-170.
- Wechsler, D. (1997a). *The Wechsler Adult intelligence scale Manual* (3rd edn). New York: Psychological Association.
- Wechsler, D. (1997b). *The Wechsler Memory Scale Manual* (3rd edn). *Manual*. San Antonio: The Psychological Corporation.
- White, K.R. (2005). Evaluation of the ecological validity of tests of executive functioning: The issue of domain-specific process skills. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 65, 3733.
- White, K.R. (2000). Relationships between executive functioning and quality of life in epilepsy surgery candidates. *Dissertation Abstracts International: Section B: The Sciences & Engineering*, 61, 1650.
- World Health Organization (2001). *Epilepsy: aetiology, epidemiology and prognosis*. Retrieved on 2 January 2007 from www.who.int/mediacentre/factsheets/fs165/en.
- World Health Organisation (WHO). (1990). *International Classification of Diseases, 10th Revision (ICD-10)*. Geneva: World Health Organisation.
- Wilson, B (1997). Cognitive rehabilitation: how it is and how it might be. *Journal of International Neuropsychological Society*, 3, 487-496.
- Winefield, H. (1982). Reliability and validity of the health locus of control scale. *Journal of Personality Assessment*, 46, 614-618.
- Zigmond, A.S. & Snaith, R.P. (1982). The hospital anxiety and depression scale. *Acta Psychiatry Scandanavia*, 67, 361-370.

APPENDICES

APPENDIX 1:

Approval Letter from Local Ethics Committee

Grampian Local Research Ethics Committee (2)

Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558503
Facsimile: 01224 558609

29 March 2007

Miss Roisin Jack
Trainee Clinical Psychologist
NHS Grampian
Clinical Neuropsychology
Ward 40
Aberdeen Royal Infirmary
Foresterhill
ABERDEEN
AB25 2ZG

Dear Miss Jack

Full title of study: Do temporal lobe epilepsy patients with memory problems experience higher external locus of control and lower quality of life than those who do not?
REC reference number: 07/S0802/10

Thank you for your letter of 26 February 2007 and email of 23 March 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has not yet been notified of the outcome of any site-specific assessment (SSA) for the research site(s) taking part in this study. The favourable opinion does not therefore apply to any site at present. We will write to you again as soon as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no study procedures should be initiated at sites requiring SSA.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out. You are advised to study the conditions carefully, in particular:

Condition 1: Annual Progress Report

Under the Central Office of Research Ethics Committees (COREC) regulations NHS Research Ethics Committees are required to monitor research with a favourable opinion. This is to take the form of an annual progress report which should be submitted to the Grampian Research Ethics Committee 12 months after the date on which the favourable opinion was given. Annual reports should be submitted thereafter until the end of the study.

Points to note:

- The first annual progress report should give the commencement date for the study. This is normally assumed to be the date on which any of the procedures in the protocol are initiated. Should the study not commence within 12 months of approval a written explanation must be provided in the 1st annual progress report.
- Progress reports should be in the format prescribed on the COREC website (www.corec.org.uk/applicants/apply/progress.htm).
- Progress reports must be signed by the Principal Investigator/Chief Investigator.
- Failure to submit a progress report could lead to a suspension of the favourable ethical opinion for the study.
- Please note the Annual Progress Report is a short 3 page form which is extremely easy to complete.

Condition 2: Notification of Study Completion/Termination

Under the Central Office of Research Ethics Committees (COREC) regulations researchers are required to notify the Ethics Committee from which they obtained approval of the conclusion or early termination of a project and to submit a Completion/Termination of Study Report. Researchers should follow the instructions on the COREC website (www.corec.org.uk/applicants/apply/endofproject.htm).

Points to note:

- For most studies the end of a project will be the date of the last visit of the last participant or the completion of any follow-up monitoring and data collection described in the protocol.
- Final analysis of the data and report writing is normally considered to occur after formal declaration of the end of the project.
- A Final Report should be sent to the GREC within 12 months of the end of the project.
- The summary of the final report may be enclosed with the end of study declaration, or sent to the REC subsequently.
- There is no standard format for final reports. As a minimum we should receive details of the end date and information on whether the project achieved its objectives, the main findings and arrangements for publication or dissemination of research, including any feedback to participants.

- Please note the Completion/Termination of Study Report need only be a summary document and should, therefore, be easy to prepare.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	5.3	18 January 2007
Investigator CV		20 June 2006
Protocol		31 August 2006
Covering Letter		26 February 2007
Letter from Sponsor		1 December 2006
Compensation Arrangements		28 July 2006
Letter of invitation to participant	2	26 February 2007
Participant Information Sheet	2	26 February 2007
Participant Consent Form	2	26 February 2007
Response to Request for Further Information		26 February 2007
Letter to Dr Gerrie	1	
CV: Fiona Summers		20 July 2006
CV: Paul Morris		

R&D approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final approval from the R&D office for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

07/S0802/10

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Dr Sheila A Simpson
Chair

Enclosures: Standard approval conditions

APPENDIX 2:

Approval Letter from Research & Development

Research and Development

Foresterhill House Annexe
Foresterhill
Aberdeen
AB25 2ZB



Date 05/04/07
Ethics 07/S0802/010
R&D Ref: 2007MH004

Miss Roisin Jack
Clinical Neuropsychology
Ward 40
Aberdeen Royal Infirmary
Foresterhill
AB25 2ZG

Enquiries to	Katy Booth
Extension	54656
Direct Line	01224 554656
Email	k.booth2@nhs.net

Dear Miss Jack,

Project title: Do temporal lobe epilepsy patients with memory problems experience higher external locus of control and lower quality of life than those who do not?

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project has R & D Management Approval to proceed locally.

Please note that if there are any other researchers taking part in the project that are not named on the original Ethics application, please advise the Ethics Committee in writing and copy the letter to us so that we may amend our records and assess any additional costs.

Wishing you every success with your research

Yours sincerely

Katy Booth
Data Co-ordinator

APPENDIX 3:

Letter of Invitation to Participate

NHS Grampian

Dr Linda Gerrie
Consultant Neurologist
Department of Neurology
Ward 40
Aberdeen Royal Infirmary
Aberdeen
AB25 2ZN

Direct Line 01224 553459
Secretary 01224 559352
Fax 01224 551188
E-mail Linda.Gerrie@arh.grampian.scot.nhs.uk



Dear

I have enclosed information about research being conducted with patients who appear to have epilepsy of temporal lobe origin. This study will explore memory and the control people believe they have over their health. It will also investigate the impact of these factors on quality of life. This research is being carried out by Roisin Jack, trainee clinical psychologist as part of her Doctorate in Clinical Psychology.

I thought you might be interested. An information sheet giving details of the study and a consent form are enclosed. If you wish to participate, please return the consent form within the next 2 weeks. A self addressed envelope has been provided.

Yours Sincerely

Dr Linda Gerrie
Consultant Neurologist
& Lead Clinician in Epilepsy

APPENDIX 4:
Patient Information Sheet

Patient Information Sheet

Study exploring the individual and combined influence of memory problems and beliefs about control over health on quality of life in temporal lobe epilepsy

You are being invited to take part in a research project. Before you decide it is important for you to understand why this research is being done and what it will involve. Please take time to read the information provided below and talk to others about the study if you wish.

What is the purpose of the study?

There is a lack of research exploring whether there is a link between memory, the amount of control people feel they have over their health and quality of life in temporal lobe epilepsy. These may be important things to consider in the care of patients with epilepsy.

Why have I been chosen?

You have been chosen because you have a diagnosis of temporal lobe epilepsy. You were identified as a possible participant by Sheena Bevan, Epilepsy Nurse and/or from the Department of Neuropsychology. It is hoped that 35 participants will take part.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

- Data for this study will be collected between February and May 2007.
- You will be asked to attend a neuropsychological assessment lasting approximately 45 minutes at either Aberdeen Royal Infirmary or Woolmanhill Hospital.
- This neuropsychological assessment will involve answering questions and completing a number of tasks exploring your memory and other thinking processes.
- All information will be kept strictly confidential. The procedures for handling, processing, storage and destruction of your data are compliant with the Data Protection Act 1998.
- Access to your medical notes will be required to check details regarding medication and diagnosis.
- If you agree to take part, you may be contacted about taking part in future studies.

Will I receive feedback?

It is anticipated that feedback regarding the overall results of the study will be given in the form of a letter and/or presentation during August/September 2007. Unfortunately, feedback on individual performance will not be provided.

What if I chose not to participate or withdraw from the study?

You are free to choose not to participate or withdraw at any time and without giving a reason. In such circumstance all identifiable material will be destroyed if you wish. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

Further Information

Please take time to consider whether or not you wish to take part. Please contact me if you would like further information:

Roisin Jack (Trainee Clinical Psychologist)
Clinical Neuropsychology, Ward 40
Aberdeen Royal Infirmary
roisin.jack@nhs.net
Tel: 01224 554350

Thank you for taking time to read this form

APPENDIX 5:

Consent Form

Patient Consent Form

Title of Study: **Study exploring whether there is a relationship between locus of control and quality of life and memory impairment in epilepsy**

Name of Researcher: **Roisin Jack**

Please initial box

- | | | |
|----|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| 1. | I confirm that I have read and understood the information sheet dated..... for the above study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily. | <input type="checkbox"/> |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. | <input type="checkbox"/> |
| 3. | I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from the NHS Trust or Edinburgh University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. | <input type="checkbox"/> |
| 4. | I agree to take part in the above study. | <input type="checkbox"/> |
| 5. | I would like to be contacted about any follow up studies. | <input type="checkbox"/> |

Name of Patient

Date

Signature

Name of Researcher

Date

Signature

Patient Identification Number for this trial:

Original Version of this document should be kept in medical notes

Upon completion Cc: Patient
Researcher Site File

APPENDIX 6:

Appointment Letter

NHS Grampian

Miss Roisin Jack
Trainee Clinical Psychologist
Department of Neuropsychology
Ward 40
Aberdeen Royal Infirmary
Aberdeen
AB25 2ZN
Direct Line 01224 554350
Secretary 01224 559352
Fax 01224 551188
E-mail roisin.jack@nhs.net



Dear

Re: Memory Functioning and Quality of Life in Temporal Lobe Epilepsy

Thank you for agreeing to participate in the above study. Your help is very much appreciated. I would like to see you for neuropsychological assessment.

Your appointment details are as follows:

Aberdeen Royal Infirmary, Ward 40
9am on Wednesday 12th April 2007

If you wear glasses please bring these with you to the appointment. Please do not hesitate to contact me if you have any queries regarding this study or if you are unable to make the above time.

Yours Sincerely

Roisin Jack
Trainee Clinical Psychologist

APPENDIX 7:
Background Information Form

Please circle the appropriate response
Space has been provided for any extra comments

1. **Gender:** Male Female

Handedness Right Left

2. **How satisfied are you with your level of social support?**

1 2 3 4 5

Very Dissatisfied Dissatisfied Neither Satisfied Satisfied Very Satisfied
Dissatisfied nor Dissatisfied

Comments: _____

3. **Employment Status:** Employed Employed Unemployed
(full time) (part time)

Comments: _____

When was your first seizure?

4. **When was the last time you had a seizure?**

Last week Last month Last 3-6 months Last year Over a year ago

Comments: _____

5. **How would you rate your epilepsy?**

Mild Moderate Severe

6. **Please tick which type of anti epileptic medication are you currently taking (trade name is written in brackets)?**

1 st Line Drugs		2 nd Line Drugs	
Carbamazepine (Tegretol)		Clobazam (Frisium)	
Ethosuximide (Zarontin)		Clonazepam (Rivotril)	
Phenytoin (Epanutin)		Gabapentin (Neurontin)	
Sodium Valproate (Epilim)		Lamotrigine (Lamictal)	
		Phenobarbitone (Gardenal/Luminal)	
		Primidone (Mysoline)	
		Vigabatrin (Sabril)	
		Topiramate (Topamax)	
		Oxcarbazepine (Trileptal)	
		Tiagabine (Gabapentin)	
		Levetiracetam (Keppra)	

7. **Do you have memory problems?** Yes No

If yes, how much do these impact on your everyday life?

Not at all Sometimes A lot

Comments: _____

Participant Number:

Date:

APPENDIX 8:

Quality of Life in Epilepsy (QOLIE-31) Version 1.0

QUALITY OF LIFE IN EPILEPSY
QOLIE-31 (Version 1.0)

Patient Inventory

Today's Date ____/____/____

Patient's Name _____

Patient's ID# _____ Gender: ☐ Male ☐ Female

Birthdate ____/____/____

Have you completed this questionnaire prior to today's visit? ☐ Yes ☐ No

MD Name _____

INSTRUCTIONS

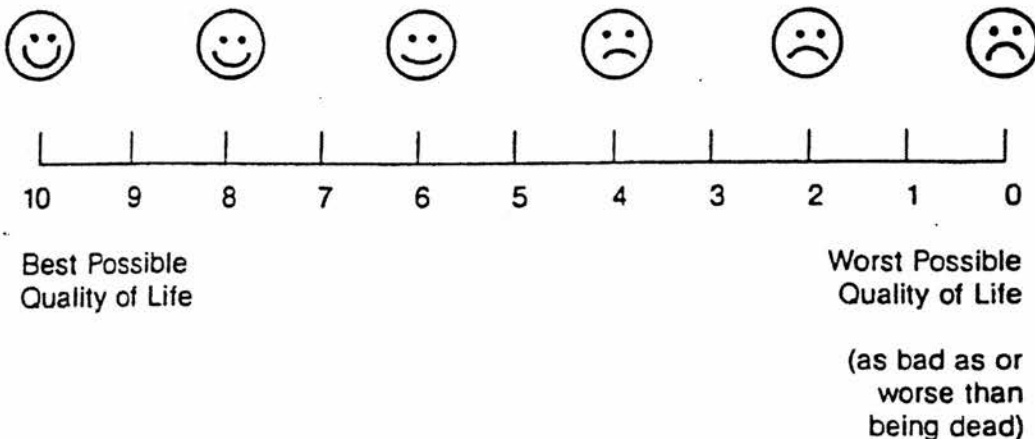
This survey asks about **your** health and daily activities. **Answer every question** by circling the appropriate number (1, 2, 3...).

If you are unsure about how to answer a question, please give the best answer you can and write a comment or explanation in the margin.

Please feel free to ask someone to assist you if you need help reading or marking the form.

1. Overall, how would you rate your quality of life?

(Circle one number on the scale below)



These questions are about how you **FEEL** and how things have been for you during the **past 4 weeks**. For each question, please indicate the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

(Circle one number on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
2.	Did you feel full of pep?	1	2	3	4	5	6
3.	Have you been a very nervous person?	1	2	3	4	5	6
4.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
5.	Have you felt calm and peaceful?	1	2	3	4	5	6
6.	Did you have a lot of energy?	1	2	3	4	5	6
7.	Have you felt downhearted and blue?	1	2	3	4	5	6
8.	Did you feel worn out?	1	2	3	4	5	6
9.	Have you been a happy person?	1	2	3	4	5	6
10.	Did you feel tired?	1	2	3	4	5	6
11.	Have you worried about having another seizure?	1	2	3	4	5	6
12.	Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5	6
13.	Has your health limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6

14. How has the **QUALITY OF YOUR LIFE** been during the **past 4 weeks** (that is, how have things been going for you)?*

(Circle one number)

A vertical ladder with 10 rungs. A stick figure stands to the left, touching the second rung from the bottom. The rungs are numbered 1 to 5 on the right side. The rungs are labeled: 1: Very well: could hardly be better; 2: Pretty good; 3: Good & bad parts about equal; 4: Pretty bad; 5: Very bad: could hardly be worse.

Very well: could hardly be better	1
Pretty good	2
Good & bad parts about equal	3
Pretty bad	4
Very bad: could hardly be worse	5

The following question is about **MEMORY**.

		Yes, a great deal	Yes, somewhat	Only a little	No, not at all
15.	In the past 4 weeks, have you had any trouble with your memory?	1	2	3	4

This question asks about **how often** in the past 4 weeks you have had trouble *remembering* or **how often** these memory problems have interfered with your normal work or living.

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
16.	Trouble remembering things people tell you	1	2	3	4	5	6

The following questions are about **CONCENTRATION** problems you may have. Circle one number for **how often** in the **past month** you had trouble concentrating or **how often** these problems interfered with your normal work or living.

		All of the time	Most of the time	A good bit of the-time	Some of the time	A little of the time	None of the time
17.	Concentrating on reading	1	2	3	4	5	6
18.	Concentrating on doing one thing at a time	1	2	3	4	5	6

The following questions are about problems you may have with certain **ACTIVITIES**. Circle one number for **how much** during the **past 4 weeks** your epilepsy or antiepileptic medication has caused trouble with...

		A great deal	A lot	Somewhat	Only a little	Not at all
19.	Leisure time (such as hobbies, going out)	1	2	3	4	5
20.	Driving	1	2	3	4	5

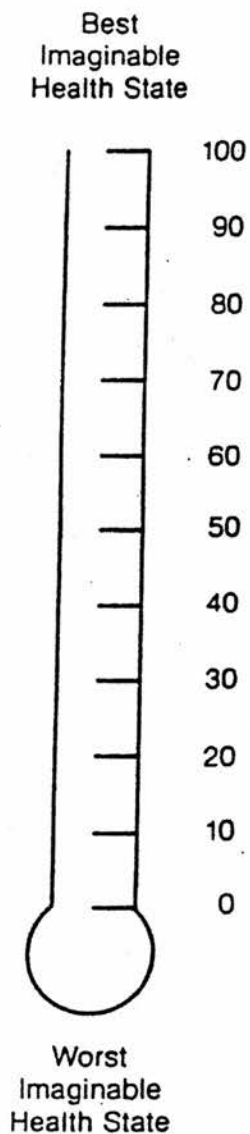
The following questions relate to the way you **FEEL** about your **seizures**.
(Circle one number on each line)

		Very fearful	Somewhat fearful	Not very fearful	Not fearful at all
21.	How fearful are you of having a seizure during the next month?	1	2	3	4
		Worry a lot	Occasionally worry	Don't worry at all	
22.	Do you worry about hurting yourself during a seizure?	1	2	3	
		Very worried	Somewhat worried	Not very worried	Not at all worried
23.	How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	1	2	3	4
24.	How worried are you that medications you are taking will be bad for you if taken for a long time?	1	2	3	4

For each of these **PROBLEMS**, circle one number for **how much they bother you on a scale of 1 to 5 (5 = Extremely bothersome)**.

		Not at all bothered				Extremely bothered
25.	Seizures	1	2	3	4	5
26.	Memory difficulties	1	2	3	4	5
27.	Work limitations	1	2	3	4	5
28.	Social limitations	1	2	3	4	5
29.	Physical effects of antiepileptic medication	1	2	3	4	5
30.	Mental effects of antiepileptic medication	1	2	3	4	5

31. How good or bad do you think your health is? On the scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. **Please consider your epilepsy as part of your health when you answer this question.**



APPENDIX 9:

Multidimensional Health Locus of Control Scale (MHLC)

Form C

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE (SD) 2=MODERATELY DISAGREE (MD) 3=SLIGHTLY DISAGREE (D)		4=SLIGHTLY AGREE (A) 5=MODERATELY AGREE (MA) 6=STRONGLY AGREE (SA)					
		SD	MD	D	A	MA	SA
1	If my condition worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my condition, what will be will be.	1	2	3	4	5	6
3	If I see my doctor regularly, I am less likely to have problems with my condition.	1	2	3	4	5	6
4	Most things that affect my condition happen to me by chance.	1	2	3	4	5	6
5	Whenever my condition worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am directly responsible for my condition getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my condition improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my condition is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my condition improves.	1	2	3	4	5	6
10	In order for my condition to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my condition is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my condition is what I myself do.	1	2	3	4	5	6
13	I deserve the credit when my condition improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following doctor's orders to the letter is the best way to keep my condition from getting any worse.	1	2	3	4	5	6
15	If my condition worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my condition will get better.	1	2	3	4	5	6
17	If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my condition improves.	1	2	3	4	5	6


[HOME PAGE](#)
[Form A](#)
[Form B](#)
[Scoring Instructions](#)
[Bibliography](#)
[FAQs](#)